

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

Ms. Robinsue Frohboese
Acting Director and Principal Deputy, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

March 30, 2021

Re: Illegal Disability Discrimination Concerning TestNebraska
Complaint filed 6-17-20

Dear Ms. Frohboese:

Please accept this letter as a supplement to the complaint filed against the State of Nebraska on June 17, 2020. We enclose a copy of our original complaint for your convenience. As you will recall, our complaint was based on two points of inaccessibility within TestNebraska, the State of Nebraska's COVID-19 testing program: (1) participation in the program requires access to the Internet, and the ability to navigate and complete an online prescreening process, and (2) participation in receiving the test itself requires the ability to drive to a testing site and wait in a line of vehicles for some time.

While both of those points of inaccessibility remain true without modification, we submit this supplement to: (1) present you with additional information about the State of Nebraska's willful and ongoing refusal to provide accommodations since the filing of our initial complaint; (2) demonstrate its ongoing impact on people with disabilities who are being denied equal access to participate in this program; and (3) add new co-complainants.

The State's Response to the Filing of OCR Complaint

TestNebraska was launched May 4, 2020. Despite repeated written requests for accommodation changes by Disability Rights Nebraska, residents with disabilities continued to be denied the benefits of the testing program. The State's failure to make reasonable modifications to the program necessitated the complaint submitted on June 17, 2020, which was joined by ten co-complainant advocacy organizations who represent people with disabilities.

Website-only screening: In response to the OCR complaint, the State of Nebraska initially added a phone number to the TestNebraska website to permit telephonic

screening for those who could not use the website. However, that option was later removed without announcement. Disability Rights Nebraska staff phoned the number in September 2020 and were advised there was no longer a phone screening option due to the high volume of calls they had received. Rather than recognizing the volume of calls demonstrated the need for a phone option, the State discontinued the phone option. In February 2021, prior to submitting this supplement, Disability Rights Nebraska phoned the number again to verify there was no change and was informed “If someone has no website access, just tell them to drive to the testing site without an appointment and they’ll take care of it there.”

Drive-in-only testing: TestNebraska sites for the general public remain drive-in-only. While the State of Nebraska has provided more in-home testing for residents of Long Term Care Facilities, there has been no modification or option offered to Nebraskans who are unable to drive to the testing sites, or remain in their cars for extended periods of time.

Nebraska Department of Health statements: In September 2020, the Nebraska Legislature convened a special hearing on issues related to TestNebraska. The Nebraska Department of Health and Human Services was represented by Incident Commander Angela Ling, who testified before the senators as follows:

“I would like to give you guys some examples of things that we have done to help with folks with disabilities. Citizens can register through the TestNebraska website. They can call the COVID hotline through DHHS and the folks on the hotline can complete the survey for them, or they can call even the Nebraska Accommodations Project hotline. They will also complete the assessment for them on the phone. We also offer on-site registration. If you’re unable to drive to the site, you can walk up. A citizen can call ACCESSNebraska and they will provide transportation to the site.”¹

Ms. Ling’s testimony was inaccurate on all points. Neither the hotlines she mentioned, nor TestNebraska, will take a COVID-19 screening call, and there is no transportation available to testing sites. The ACCESSNebraska program is the Medicaid / SNAP program; they have nothing to do with transportation assistance. Disability Rights Nebraska staff contacted Ms. Ling after her testimony to inquire further about these assertions and learned that had no personal knowledge of the accuracy of this information.

The complainants agree that the options of a hotline for screening and state assistance in transportation to testing sites would be appropriate accommodations. The fact that

¹ LR 394 Hearing Transcript, 9-28-20, page 101. Available online: <https://www.nebraskalegislature.gov/FloorDocs/106/PDF/Transcripts/Appropriations/2020-09-28.pdf>

state DHHS officials have conceived of these options, testified they are available, and yet not actually made such accommodations in the last year is egregious.

Governor Pete Ricketts' statements: The State's willful and deliberate intent to exclude Nebraskans with disabilities from the TestNebraska program are most starkly shown by the response by Governor Pete Ricketts. On November 25, 2020, Governor Ricketts was asked at his regular press conference about a report issued by Disability Rights Nebraska that highlighted the ongoing inaccessibility of TestNebraska. In response, Governor Ricketts said:

“So just in general for those who are disabled, they should access testing through the regular health care system that they would normally. That system really hasn't changed at all, their providers should be able to help with that. With regard to Test Nebraska, we do have 53 sites set up around the state. Many of these sites are in places like hospitals, clinics, and local public health departments, where anybody would be able to access health care services normally. So, a disabled person that was leveraging a clinic could still go there or if that clinic was one of our contractors or the hospital or whatever, so that's an opportunity there. With regards to our Test Nebraska sites that we have for example here in Lincoln and Omaha, we try to site them near public transportation so we make it accessible that way. You can walk up to those sites. If you're in a wheelchair in a car, we'll get into the car to do the testing. We'll make the accommodations. Another opportunity is through the Visiting Nurse Association we have a relationship with them. So that would be another way if people are looking to the Visiting Nurse Association to come to their home they can do it that way. So there's a variety of different ways to do it.”²

Governor Ricketts intends people with disabilities to be tested through some mechanism other than TestNebraska such as their private health provider or by paying a service such as a visiting nurse. This follows his earliest comments in response to concerns about the inaccessibility of TestNebraska from June 2020, where the Governor said “What we needed to do is to continue to work on getting the system down for the regular customers, so to speak, if you want to think about it – the drive-up customers that the system was originally designed to serve. And we will be flexible with regard to how we're serving other populations to be able to do that.”³

² Governor press conference, 11-25-20. Available online: <http://netnebraska.org/interactive-multimedia/news/11252020-governors-news-conference>

³ Fred Knapp, “Disabled Advocates Say TestNebraska Not Accessible,” NET Nebraska, 6-1-20. Available online: <http://netnebraska.org/article/news/1221753/disabled-advocates-say-testnebraska-not-accessible>

The Governor has been aware for more than 10 months that Nebraska's testing program presents barriers to persons with disabilities, yet he remains unwilling to make the reasonable modifications necessary to ensure the program is accessible. As the quote above illustrates, the Governor continues to argue that disabled residents should bear the burden of finding testing options in the general health care system, outside the State's free testing program. This blatant and continuing disregard for the State's obligations under the ADA and Section 504 of the Rehabilitation Act is egregious, and warrants the attention of OCR.

The Ongoing Impact on Nebraskans with Disabilities

As outlined in our initial complaint, TestNebraska's inaccessibility has a wide-reaching impact on Nebraskans with a range of disabilities. Here are a few examples of Nebraskans facing barriers:

1. Amy Buresh of Lincoln, Nebraska, is blind. Her husband is also blind. They have two young children. In November 2020, everyone except the six-year-old were experiencing serious COVID-19-like symptoms. Since the family could not ask a friend or ride share service to give them a ride to a testing site if they were potentially contagious, Ms. Buresh called TestNebraska to see what they could offer. Ms. Buresh described her experience: "They couldn't help me and I was feeling much sicker so then my husband decided to call Lancaster County Public Health Department to ask what our options were," said Ms. Buresh. "There was nothing on the website for TestNebraska or on the state's COVID-19 page that said there was an option for in-home testing, but we are both active in the National Federation of the Blind of Nebraska (NFB). I serve on the national board of directors of NFB and knew first-hand about the Federation's advocacy in other states that resulted in new policies offering in-home testing. The county told us to reach out to Tabitha Health, who they were contracting with. It took a lot of calls and extra work to set it up, but about three days later Tabitha came to our home to test the whole family. The results came back negative, but between the extreme fatigue and my significant loss of taste and smell, I knew I better check again. About a week later, I registered for a drive-through test from TestNebraska and asked my friend's teenage daughter to drive me. Since the young woman had already tested positive herself, she wasn't worried, but we both wore masks due to the uncertainty of my own status. I didn't really like having to rely upon her help, but I'd been so discouraged by the wait and the difficulty in getting someone to offer in-home testing the first time, I just had to come up with the workaround to get to the official drive-through testing site. I've spoken with other members of the National Federation of the Blind of Nebraska to urge them to call their county health departments to ask for in-home testing since no one is

advertising that as a possibility. Even though I'm glad people are learning to support one another, we shouldn't have to rely on word of mouth tips to gain access to testing."

2. Dea Henke of Lincoln, Nebraska, described her experience in our initial complaint: she has muscular dystrophy and cognitive difficulties so while she is capable of driving, she does not feel safe driving without a passenger to ensure she does not become lost. At the time of our complaint, she was experiencing COVID-19-like symptoms but was unable to go to a testing site for fear of exposing a passenger or driver to the virus. She uses a ventilator and in light of her underlying health conditions that make her more vulnerable to COVID-19, she decided in August 2020, to drive herself alone to the designated testing site. Due to her cognitive disability, Ms. Henke became confused as she pulled away from the testing station. "There were a lot of concrete barriers and one way signs, and I just couldn't figure out how to get out of there. I drove around for twenty minutes, came back to the entrance but the lady just told me I couldn't leave that way and wasn't helpful. Finally I had to leave by going out the wrong way on a street. I knew I shouldn't have been driving alone but they had left me no choice."
3. Lisa Johnson of Omaha, Nebraska, was born blind and had a cornea transplant in 2018 which has given her some sight but required that she now take immunosuppressant drugs which make her more vulnerable to COVID-19. Lisa and her husband are parents to 7 children, ages 4 through 15. Normally, Lisa relies upon her sighted husband or ride share services when she or the children need transportation to a medical appointment, but in August 2020, he was away on a work trip when Lisa was informed by a contract tracer that she'd been exposed to COVID-19. Lisa said, "While I wanted to be tested, there was no way to navigate that situation safely and ethically, so I just stayed at home. While that meant I was keeping my co-workers safe, I worried I was inadvertently exposing my children to the virus. What was I to do between choosing to expose a stranger from Uber or Lyft to the virus between exposing my children while I waited to see if symptoms emerged? It's an impossible choice that no one should have to make."

New Co-signers to the Complaint

The National Federation of the Blind (NFB) is the oldest, largest and most influential membership organization of blind people in the United States. With tens of thousands of members, and affiliates in all fifty states, the District of Columbia, and Puerto Rico, the ultimate purpose of the NFB is the complete integration of the blind into society on an equal basis. Since its founding in 1940, the NFB has devoted significant resources toward advocacy, education, research, and development of programs to ensure that blind individuals enjoy the same opportunities enjoyed by others.

The National Federation of the Blind of Nebraska is an affiliate of the NFB. These organizations have members who have experienced barriers to TestNebraska and accordingly wish to add both organizations as co-signers to the pending complaint.

Necessary Modifications to Resolve This Complaint

As outlined in our original complaint, other jurisdictions have created appropriate modifications to their COVID-19 testing programs to provide access for people with disabilities. More recently, we've seen modifications made to vaccination programs to improve access to individuals with disabilities. In addition to those cited in our previous complaint, we suggest the state of Nebraska could look to the following models:

- Oswego County in rural New York state will drive eligible individuals for testing if they are without transportation.⁴
- Delaware is using their existing para-transit services to bring COVID-19 services to individuals with disabilities in their homes.⁵
- Massachusetts has expanded access to its Medicaid non-emergency transportation service, The Ride, in order to facilitate access to vaccination sites for MassHealth members. Massachusetts has also added telephone scheduling capacity as an alternative to its web-based appointment process.⁶
- Austin, Texas offers curb-to-curb rides through their paratransit public transportation service for people with disabilities.⁷
- New York City's Department for the Aging is using their paratransit service to offer free rides as well as ambulette services for people with more significant health or physical concerns.⁸

⁴ https://health.oswegocounty.com/news_detail_T28_R107.php

⁵ Page 2: <https://dhss.delaware.gov/dhss/ddds/files/letter01112021.pdf>

⁶ FAQ on transportation to vaccine appointments for MassHealth members: available at <https://www.mass.gov/doc/transportation-to-covid-19-vaccine-appointments-for-masshealth-members-and-health-safety-net-0/download>

⁷ Taylor Moore, "If you can't get to your vaccine appointment, these cities will drive you," Next City (February 17, 2021). Available online: <https://nextcity.org/daily/entry/if-you-cant-get-to-your-vaccine-appointment-these-cities-will-drive-you>

⁸ Id.

- Miami Beach Fire Rescue is visiting individuals who cannot leave their homes for the vaccine.⁹
- Lincoln, Nebraska is offering free rides to vaccination sites with the city's public transportation shuttles.¹⁰

A complete list of transportation options that have been implemented by small, medium and large municipalities can be found online as models for Nebraska.¹¹

Nebraska can resolve this complaint by making three simple modifications:

- Restore the phone option to register for TestNebraska that offers a live operator who will assist callers to sign up for testing.
- Put information about the option of in-home testing on the state's website so individuals unable to drive to a testing site can request a visit at their residence for testing.
- Facilitate transportation access to TestNebraska sites by making existing state and federally funded non-emergency transportation and para transit programs available to residents who are able to travel to a State-operated testing site.

While these modifications have been raised multiple times in letters and during in-person meetings with leadership of the Department of Health and Human Services in the last ten months, no action has been taken on either point. We therefore repeat our request for investigation and resolution by this office.

Conclusion

The legal standards cited in our June 17, 2020 complaint remain the basis for our request that the Office for Civil Rights investigate and issue findings that the actions taken by Governor Ricketts and his administration unlawfully discriminate against persons with disabilities in Nebraska.

Almost a year has passed since the initial declaration of COVID-19 as an emergency pandemic, and the particularly lethal effects of COVID-19 on individuals with disabilities is well-known. Accessing to testing remains key to protecting vulnerable members of

⁹ Id.

¹⁰ City of Lincoln: <https://www.lincoln.ne.gov/News/2021/2/10b>

¹¹ "Examples of Transportation's Role in Vaccination Efforts," National Center for Mobility Management. <https://nationalcenterformobilitymanagement.org/covid-19-resource-center/>

our community, especially in light of new COVID-19 variants spreading across the country. The State's failure to make TestNebraska accessible to people with disabilities is not just a violation of federal law—it is evidence of a willful refusal to make modifications that are necessary to save lives.

We request the assignment of an investigator to act as liaison with the undersigned and the Office for Civil Rights. We greatly appreciate your investigation and prompt response to this matter. We stand ready to provide any additional information that you require.

Respectfully,

Eric A. Evans, Ph.D.
Chief Executive Officer
Disability Rights Nebraska
134 South 13th Street, Suite 600
Lincoln NE 68508
Eric@drne.org
402-474-3183

Kathryn Rucker
Senior Attorney
Center for Public Representation
22 Green St.
Northampton MA 01060
krucker@cpr-ma.org
617-965-0776

Shira Wakschlag
Director, Legal Advocacy
The Arc
1825 K Street, NW, Suite 1200
Washington DC 20006
wakschlag@thearc.org
202-534-3708

Mark Riccobono
President
National Federation of the Blind
200 East Wells Street
Baltimore MD 21230
Officeofthepresident@nfb.org
410-659-9314

Together with:

Edison McDonald
Executive Director
The Arc of Nebraska
Lincoln Community Foundation
215 Centennial Mall S, Ste 100
Lincoln NE 68508
edison@arc-nebraska.org
402-475-4407

Peggy Reisher
Executive Director
Brain Injury Alliance
P.O. Box 22147
Lincoln NE 68542
peggy@biane.org
(c) 402-8901-0606
(o) 402-423-2463

Amanda Vazquez
Government Relations Director
Paralyzed Veterans of America
Great Plains Chapter
7612 Maple St.
Omaha NE 68134
vazquez@greatplainspva.org
402-398-1422

Mary Angus
ADAPT NE
Mary.Angus2@gmail.com
402-699-0578

Travis Schaffer
President of the Board
People First of Nebraska, Inc.
P.O. Box 5292
Grand Island, NE 68802
PeopleFirstNebraska@outlook.com
402-559-4892

Kathy Hoell, MPA
Executive Director
Nebraska Statewide Independent Living Council
kathy@nesilc.org
402-438-7979 voice
402-677-6662 cell

Mark Bulger
President
American Council of the Blind of Nebraska
P.O. Box 6506
Omaha, NE 68106-0506
info@acbnebraska.org
402-201-0163

Amy Buresh
President
National Federation of the Blind of Nebraska
president@ne.nfb.org
402-477-7711

cc: Ari Ne'eman, OCR
Pam Barron, OCR