

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

Sent Via Electronic Mail & U.S. Mail

June 17, 2020

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

RE: **Illegal Disability Discrimination Concerning TestNebraska**

Dear Mr. Severino:

Please accept this letter as a complaint against the State of Nebraska for failing to make reasonable modifications to TestNebraska, the State of Nebraska's COVID-19 testing program. Through TestNebraska, the State assesses individuals' level of risk for being infected with COVID-19 and provides testing to individuals screened as high-risk at drive-through sites throughout the state.¹ Participation in TestNebraska requires access to the internet to complete the prescreening, and 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. Many people with disabilities, including people who have intellectual and developmental disabilities (I/DD), are blind, or are in institutional or congregate facilities like nursing homes and assisted living, are unable to drive and lack access to other transportation, and thus are unable to participate in TestNebraska. By failing to make reasonable modifications to the TestNebraska program, the State is discriminating against individuals with disabilities who are being denied equal access to participate.

People with disabilities are already at a significantly higher risk of contracting COVID-19 and experiencing life-threatening complications from the virus.² It is critical that people with disabilities are able to obtain this crucial testing. Individuals with disabilities who live in Long Term Care facilities³ (LTCs), Intermediate Care Facilities (ICFs), Assisted

¹ *Get Nebraska Back on Track with State-wide COVID-19 Testing*, TestNebraska.com (last visited June 17, 2020), available at <https://www.testnebraska.com/en>.

² Centers for Disease Control and Prevention, People with Disabilities, <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>

³ Centers for Disease Control and Prevention, Testing Guidelines for Nursing Homes, <https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-homes-testing.html>

Living Facilities (ALFs)⁴, and group homes are at an increased risk of both contracting COVID-19 and dying from the virus.⁵ While nursing homes have come under national spotlight during the pandemic⁶, the increased scrutiny for infection rates and their testing has not been extended to ICFs, group homes or facilities that care for individuals with IDD.⁷ Individuals with IDD are four times as likely to contract COVID-19 than the general public, and almost two times as likely to die of the virus.⁸ This increased risk in individuals with disabilities is attributed to a higher rate of preexisting health conditions and their higher rates of living in closer proximity to others.⁹ About 13% to 20% of people with IDD live in such settings, in comparison to about 6% of people over the age of 65.¹⁰ These living settings make social distancing, a key factor in preventing the spread of COVID-19, nearly impossible.¹¹ These factors are compounded by race: across the United States, African Americans are dying of COVID-19 at a rate of more than twice their population share.¹²

Nebraska's failure to make reasonable modifications to TestNebraska is literally placing the lives of people with disabilities at unnecessary risk. We urge you to immediately investigate and take swift action to remedy these allegations of disability discrimination.

This complaint is filed by Disability Rights Nebraska¹³ along with the advocacy organizations listed below on behalf of their constituents, Nebraskans with disabilities,

⁴ Centers for Disease Control and Prevention, Considerations for Prevention of COVID-19 in Assisted Living Facilities, <https://www.cdc.gov/coronavirus/2019-ncov/hcp/assisted-living.html>

⁵ Joseph Shapiro, *COVID-19 Infections and Deaths are Higher Among Those with Intellectual Disabilities*, Nat'l Public Radio (June 9, 2020), available at: <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabilities> And%20here%20is%20a%20recent%20letter%20citing%20even%20more%20about%20high%20risk%20in%20ICF,%20etc.%20http://www.c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-COVID19-and-CMS-nursing-home-safety-initiative-5-5.20-to-CMS.pdf.

⁶ Jemima McEvoy, *Nursing Homes Account for Over 40% of U.S. Coronavirus Deaths*, Forbes, (June 16, 2020), available <https://www.forbes.com/sites/jemimamcevoy/2020/06/16/nursing-homes-account-for-over-40-of-us-coronavirus-deaths/#6f2b2b52300b>

⁷ Holbrook Mohr, et al., *Thousands Sick from Covid-19 in Homes for the Disabled*, The Associated Press, (June 10, 2020), available at: https://apnews.com/bdc1a68bcf73a79e0b6e96f7085ddd34?utm_medium=AP&utm_source=Twitter&utm_campaign=SocialFlow&fbclid=IwAR2o1AOeJT2y_6ifQFME9Mxp2WpWvjyIMkUvrJOisSV3ZTeSH_PgZxYSj0c.

⁸ Shapiro, *supra*.

⁹ *Id.*

¹⁰ *Id.*

¹¹ Mohr, *supra*.

¹² See, e.g., APM Research Lab, *The Color of Coronavirus* (Apr. 28, 2020), <https://www.apmresearchlab.org/covid/deaths-by-race#black>.

¹³ Disability Rights Nebraska is the Protection & Advocacy system ("P&A"), as that term is defined under the Developmental Disabilities Assistance and Bill of Rights Act ("DD Act"), 42 U.S.C. § 15041 *et seq.*, the

who, like the individual examples described below, are being denied their right to equal access to TestNebraska. 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). This action is brought under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.

Background

Nebraska’s mobile testing site initiative, TestNebraska, launched on May 4, 2020.¹⁴ Participation in TestNebraska requires access to the internet to complete the prescreening. Some Nebraskans with disabilities do not have access to the internet in the congregate facility where they live. Some Nebraskans with disabilities who live independently do not have a computer or internet access at home. Some Nebraskans with disabilities—particularly those with IDD or cognitive age-related disabilities—lack the ability to use the internet. Participation in receiving the test itself requires the ability to drive to the testing site. Many people with disabilities do not drive or have access to non-emergency transportation. In addition, the testing sites sometimes have wait lines that require a significant amount of time in a vehicle which can be challenging for many people with disabilities. As of the date of this filing, the State has made little or no provision for any testing options for individuals who lack access or are unable to use the website screening and/or unable to drive themselves independently or get transportation to the testing sites. Governor Ricketts has characterized TestNebraska as “designed to serve” drive-up customers, who he calls “the regular customers.”¹⁵

The State of Nebraska has failed to make adequate modifications for Nebraskans with disabilities, despite repeated requests from Disability Rights Nebraska, local advocacy

Protection and Advocacy for Individuals with Mental Illness Act of 1986 (“PAIMI Act”), 42 U.S.C. § 10801 *et seq.*, and the Protection and Advocacy of Individual Rights Act (“PAIR Act”), 29 U.S.C. § 794e *et seq.*

¹⁴ Gov. Ricketts Highlights Launch of “Test Nebraska” Mobile Testing Sites, Announces Childcare Referral Program, Neb. Gov’t (May 4, 2020), available at: <https://governor.nebraska.gov/press/gov-ricketts-highlights-launch-%E2%80%9Ctest-nebraska%E2%80%9D-mobile-testing-sites-announces-childcare>

¹⁵ Fred Knapp, *Disabled Advocates say Test Nebraska not Accessible*, Neb. Educ. Telecomm.’s (June 1, 2020), available at: <http://netnebraska.org/article/news/1221753/disabled-advocates-say-testnebraska-not-accessible>. See also, Martha Stoddard, *Disabled Nebraskans seek access to 27 million coronavirus testing program*, Omaha World Herald (June 1, 2020), available at: https://www.omaha.com/livewellnebraska/disabled-nebraskans-seek-access-to-27-million-coronavirus-testing-program/article_df73d64b-5337-5d29-a9df-53c139384266.html.

groups, and state lawmakers. Disability Rights Nebraska first requested accommodation plans for the pandemic's impact on people with disabilities by letter on March 13, 2020 (Attached as Exhibit A at pgs. 1-2). Since then, Disability Rights Nebraska has specifically raised the need for accessible testing in meetings with the Nebraska Department of Health and Human Services leadership and in letters dated May 7th, May 29th and June 4th. *Id.* at pgs. 2-11.

The Statewide Independent Living Council (SILC) reached out to Senator Carol Blood about the inaccessibility of TestNebraska. In response, Senator Blood held a listening session on the issue of testing accessibility on June 1st. The Arc of Nebraska has circulated a public petition calling for accessible testing. Despite these many voices putting the state on notice, TestNebraska remains accessible only for Nebraskans with the ability to access the internet and drive a vehicle.

The State's failure to offer options to Nebraskans with disabilities who do not have internet access and/or cannot drive has had significant impact on a wide variety of people. Disability Rights Nebraska has been conducting remote monitoring of institutional and other long term care facilities like group homes for people with IDD and assisted living facilities for people with mental illness across the state and interviewing Nebraskans with disabilities about their experiences, which has resulted in the following examples of Nebraskans facing barriers to accessing TestNebraska:

1. A guardian for an adult living in a Long Term Care nursing facility contacted Disability Rights Nebraska to describe their experience. The guardian was informed there was a positive COVID-19 diagnosis in the home where the ward was living. The person under guardianship does not have the technology or the knowledge to complete an online form such as is required for TestNebraska, so the guardian completed the form with the information appropriate for the affected person. The TestNebraska site indicated testing was warranted, but the LTC staff had no ability to transport the individual to receive the test. The guardian made multiple calls to try to arrange transportation to the test site, but was unable to find anyone willing to place the person who was possibly COVID-19 positive in their car for the drive.
2. The CEO/administrator of a Long Term Care nursing facility spoke with Disability Rights Nebraska about their residents' plight. There have been multiple deaths from COVID-19 in this LTC, and several other residents had been transported to the hospital in an ambulance for serious symptoms of the virus and tested positive. The LTC facility does not have accessible vans to transport all of their residents to the mobile testing site in their town, all of whom are identified as high-risk due to the cases of COVID-19 in the facility.

3. Dea Henke of Lincoln, Nebraska lives with a form of muscular dystrophy. She lives independently and owns a vehicle but several months ago she realized she was experiencing some cognitive difficulties and was no longer safe to drive alone since she becomes easily confused and lost even on familiar streets. When she developed some concerning symptoms including fatigue, muscle aches, a sore throat and nausea to the point of vomiting, she called her personal doctor. Her doctor told her to go online and take the TestNebraska questionnaire. She did and was informed she should be tested. Ms. Henke called her doctor back to explain she could not do the drive-through test since she cannot safely drive alone. If she took someone with her, she might expose them to her virus. Her doctor told her the only option for her was to stay at home and wait to see if the symptoms became bad enough to merit a trip to the emergency room in an ambulance. Ms. Henke uses a ventilator at night to aid in her breathing and is worried about her symptoms which have not subsided as of the filing of this complaint. She is aware that her disability puts her at greater risk if she does contract COVID-19 but has no guidance on how to navigate the TestNebraska drive through test.

4. A group home for adults with developmental disabilities has had several individuals tested when their symptoms became acute enough to require transportation to the local hospital for care and COVID-19 testing. Other individuals in the group home are assessed as high risk but the CEO said they do not have transportation to test these individuals at their local mobile testing site, despite several positive tests of others in the group home.

5. One administrator for an assisted living facility for adults with mental illness in rural Nebraska said they had no idea how they would handle getting their residents to a mobile testing site since none of the residents had the ability to drive themselves and there was no public transportation in their city. The administrator said no one from the state or county had provided any instructions on whether they should have their residents tested, nor how to access the testing.

6. Stacy Cervenka and her husband live in Lincoln, raising young children. They are both blind and therefore don't drive. They worry how they would access TestNebraska for themselves or their children if one of them started showing symptoms of COVID-19. All their extended family live hundreds of miles away. Public transportation or services such as Uber and Lyft are not a feasible or ethical option because they don't want to expose anyone else to their symptoms. She recently got a call from her son's day camp that he has an unexplained rash and, due to COVID concerns, he can't return to day camp until he has a doctor's note that it's safe for him to do so. Her doctor will be able to schedule a telehealth appointment, but if the doctor determines that he needs to get tested, she is concerned that she won't be able to access her local mobile testing site.

Legal Standards

Title II of the ADA prohibits public entities (such as state and local governments) from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Unlawful discrimination under Title II includes, *inter alia*: using eligibility criteria that screen out or tend to screen out individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8).

Moreover, the United States Department of Justice has explicitly instructed that Title II of the ADA applies to emergency preparedness efforts of state and local governments, writing:

One of the primary responsibilities of state and local governments is to protect residents and visitors from harm, including assistance in preparing for, responding to, and recovering from emergencies and disasters. State and local governments must comply with Title II of the ADA in the emergency and disaster-related programs, services, and activities they provide.¹⁶

Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including Nebraska's state agencies and most hospitals and health care providers. 29 U.S.C. § 794(a). The breadth of Section 504's prohibition on disability discrimination is co-extensive with that of the ADA including failing to make reasonable modifications in policies, practices or procedures when necessary to avoid discrimination. See, *Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *Layton v. Elder*, 143 F.3d 469 (8th Cir. 1998).

The Office for Civil Rights' March 28, 2020 Bulletin specifically discusses the obligations of entities covered under federal disability laws to ensure equal access to medical treatment and "effectively address[] the needs of at-risk populations."¹⁷ This includes

¹⁶ DOJ, Emergency Management Under Title II of the Americans with Disabilities Act at 1 (July 26, 2007), available at <https://www.ada.gov/pccatoolkit/chap7emergencygmt.htm>. See also, Department of Health and Human Services (HHS) Office for Civil Rights, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease (COVID-19), 1-3 (Mar. 28, 2020) available at: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog (hereinafter "OCR Bulletin").

¹⁷ OCR Bulletin at 2.

providing effective communication, meaningful access to information, and making reasonable modifications to address the needs of individuals with disabilities.¹⁸

TestNebraska is wholly at odds with the non-discrimination standards cited above. Nebraska is excluding tens of thousands of people with disabilities from equal access to the benefit of the State's TestNebraska services. Despite repeated requests from complainants, Nebraska has refused to make the reasonable modifications to TestNebraska that are necessary to provide access to people with disabilities, many of whom are at highest risk for COVID-19.

Specifically, TestNebraska's drive-through testing program fails to provide testing for individuals with disabilities who do not have transportation to testing sites and/or wait in lines of vehicles at the testing sites. Many individuals with disabilities do not drive or have access to non-emergency transportation to allow them to travel in person to a testing site. Other individuals with disabilities have complex self-care needs or require assistance with their activities and instruments of daily living, which prevents them from traveling or waiting in long lines. These and other issues are preventing individuals with disabilities from accessing the drive-through testing sites.

Nebraska has failed to put modifications in place to reasonably accommodate qualified individuals with disabilities from the opportunity to participate in TestNebraska. 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 home.¹⁹ 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 test.²⁰ Many states provide testing at nursing homes and other long term care facilities.²¹ 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.

¹⁸ *Id.*

¹⁹ Ryan Nicol, *Broward County to provide in-home Covid-19 testing for elderly and disabled*, Fla. Politics, (May 5, 2020) available at: <https://floridapolitics.com/archives/331038-broward-in-home-covid-testing>; Miami Gov't, *City Launches In-Home Covid-19 Testing Service for Homebound Seniors* (Mar. 23, 2020) available at: <https://www.miamigov.com/Notices/News-Media/City-Launches-In-Home-COVID-19-Testing-Service-for-Homebound-Seniors>.

²⁰ Anavid Reyes, *How people without vehicles, disabilities are getting testing for Covid-19*, KPRC Click2Houston, (May 21, 2020) available at: <https://www.click2houston.com/traffic/2020/05/21/how-people-without-vehicles-disabilities-are-getting-tested-for-covid-19/>.

²¹ See, e.g., "Governor Announces Universal Testing in Long-Term Care Facilities" available at <https://coronavirus.delaware.gov/long-term-care-facilities/>.

The State of Nebraska must take the following immediate actions:

--Issue a directive that individuals with disabilities who are unable to travel to TestNebraska testing sites will be provided with COVID-19 testing, including through mobile testing at individuals' residences and/or by providing accessible transportation at no cost;

--Expand TestNebraska testing capacity to meet the needs of individuals with disabilities;

--Offer a screening process that does not require internet access;

--Implement policies and procedures and make reasonable modifications to ensure that persons with disabilities have equal opportunity to access TestNebraska;

Accordingly, Disability Rights Nebraska requests that the Office for Civil Rights immediately investigate and issue findings that the actions taken by Governor Ricketts and his administration unlawfully discriminate against persons with disabilities in the state of Nebraska. We further request that OCR advise Nebraska that it must make reasonable modifications to TestNebraska so that people with disabilities, who face significantly heightened risks during this pandemic, are able to access this program.

We greatly appreciate your prompt consideration of this urgent matter. We can be contacted at the numbers/emails below concerning any questions or responses to this Complaint.

Respectfully,

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Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

Exhibit A

Via Hand Delivery

March 13, 2020

Chief Executive Officer Dannette R. Smith
Nebraska Department of Health and Human Services
301 Centennial Mall South
Lincoln NE 68509

Re: NDHHS Planning and Response to COVID19

Dear CEO Smith:

I am writing in regards to the state plan for COVID19. We appreciate that the Department has worked quickly to provide comprehensive information to the public. My purpose here is to ensure that the information available from and response by the Department fully covers the specific needs of Nebraskans with disabilities, whether they are living independently in the community or in provider-operated facilities.

As you continue to develop and/or adjust statewide plans for responding to a widespread health outbreak, the State's response must take into consideration the requirements under the Americans with Disabilities Act, Section 504 and the Olmstead decision as these apply specifically to the needs of people with disabilities. The current situation raises a number of questions in this regard, for example:

- Are there shelter in place protocols for people with disabilities?
- Do all group homes, institutional facilities, jails, prisons and detention centers have a two week supply of necessary items on site?
- If essential services are disrupted statewide, what support will be offered to individuals with disabilities?
- Are providers in facilities and group homes being trained on how to comply with government guidance while also complying with the ADA, Section 504 and Olmstead?
- Are providers in facilities and group homes being trained on how to identify the symptoms of COVID19 while simultaneously balancing privacy and accommodation needs under the ADA?
- Is there a plan in place for staffing shortages if employees of facilities and group homes become ill? Where will patients go if a facility or home becomes nonoperational?
- Are all residents of facilities, group homes, jails, prisons and detention centers being granted access to Kleenex, handwashing stations, wet wipes, sanitizer?

We are particularly concerned about individuals in seclusion or restraint (including segregation in the corrections setting) having access to hygiene supplies.

- Are all facilities, group homes, jails, prisons and detention centers aware of their ongoing need to provide access to appropriate assistive technology as needed to residents?
- Are all facilities, group homes, jails, prisons and detention centers making information available to the residents about their rights and information on hygiene education?
- Are all facilities, group homes, jails, prisons and detention centers ensuring that staff have identified individuals who are immunocompromised to ensure they are not placed in contact with any individuals with COVID19 exposure?
- Is there a tracking process in place to identify individuals who are institutionalized or medically isolated?

I would also like to suggest for your consideration that, after the current emergency has subsided, we meet with your staff and other relevant stakeholders to have a conversation about long term future planning for any similar health emergency to ensure that the plans and responses comprehensively take into consideration Nebraskans with disabilities. The unexpected and unprecedented nature of this issue will inevitably provide important lessons that will help in crafting new protocols for the future.

Again, we thank you and your staff for their work so far to address this immediate health crisis and look forward to any expanded information you may share with the public to protect Nebraskans with disabilities.

Sincerely,



Eric A. Evans, Ph.D.
Chief Executive Officer

cc: Major General Daryl Bohac, Nebraska Emergency Management Agency



May 7, 2020
VIA EMAIL

CEO Dannette Smith
Nebraska Department of Health and Human Services
301 Centennial Mall South
Lincoln NE 68509

Dear Ms. Smith:

Thank you again for speaking with us last week about the issues relating to Nebraskans with disabilities during COVID19. We saw your memo affirming the Office of Civil Rights guidance and were so pleased to be able to share that with the other advocates and stakeholders across the state. Your leadership and firm action are greatly appreciated.

We wanted to follow up on our call with a few resources and questions as promised.

Long term care outbreak data transparency: Our immediate neighbors Colorado and Iowa are both publicly sharing information that lists specific positive testing in Long Term Care facilities:

Iowa's roster is here as a sample; you'll see they've listed the facilities with outbreaks (23) by name without sharing patient identifying information:

https://public.tableau.com/views/IowaCOVID19/LTCDashboard?iframeSizedToWindow=true&:embed=y&:render=false&:display_count=n&:showAppBanner=false&:origin=viz_share_link Colorado's data is reporting all outbreaks, not just outbreaks in nursing homes: <https://covid19.colorado.gov/data/outbreak-data>.

Providing this facility-specific information publicly has several advantages: first, it allows advocates to provide additional support and review of the site for unmet needs. Second, it alerts families so they can take additional preventative measures if they had any contact and may be an asymptomatic carrier. Third, enhanced general awareness of the particularly deadly effects of COVID19 may encourage ongoing compliance with social distancing guidelines. We are concerned that without the full picture of how many Nebraskans are diagnosed with COVID19, the small number of people wanting to "return to business as usual" will not understand why restrictions remain essential.

Information dissemination: In our call, you mentioned having distribution lists for reaching facilities and providers across the state. We have seen at least one such email

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distribution list for agencies providing services to people with developmental disabilities. Are there such electronic lists such as a listserv or email distribution list for other service providers such as ALFs and LTC facilities, or is the only way to communicate with those categories through the postal service? In the rapidly changing landscape of a health crisis, we're realizing that electronic communication across the breadth of the state seems to be a missing component and we'd like to brainstorm creating regulations that would require every licensed facility to maintain an unchanging email address (i.e., not tied to a specific employee's name who may resign or retire) for swift communication in the future.

Increased testing: As we touched on in our call, we're hearing across the state that LTC, ALF and ICF-DD facilities have had only a handful of staff or residents tested for COVID-19. Given what we know about this virus' rapid movement in such congregate living facilities in other states, we are concerned at the very low numbers of testing individuals in these settings. Expanded testing with the National Guard or mobile testing from hospitals are promising developments in the state, but they appear to be relying upon having the test taker come to the test site. For individuals living with disabilities in a group setting, that is unlikely to be feasible. We're hoping the state can begin to roll out mobile testing that travels to the LTC, ALF and ICF-DD facility to do testing of all residents proactively without waiting for symptoms.

We'll continue our surveying work over the next two weeks and compile any additional ideas or concerns for consideration in advance of our next call. Thanks to you and all of your staff for your responsiveness to the items we've identified. We look forward to continuing to work with you.

Sincerely,

Eric A. Evans, Ph.D.
CEO, Disability Rights Nebraska

Cc: Emily Dodson, Chief of Staff
Tony Green, Director, Division of Developmental Disabilities

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

May 29, 2020
VIA EMAIL

CEO Dannette Smith
Nebraska Department of Health and Human Services
301 Centennial Mall South
Lincoln NE 68509

Dear Ms. Smith:

We appreciate the opportunity to speak with Tony Green and Emily Dodson on an ongoing basis about the issues relating to Nebraskans with disabilities during COVID19. I'm writing to just memorialize the items we discussed on May 24th for future discussion.

Long term care outbreak data transparency: We previously provided you with the examples of the COVID19 outbreak dashboards in use by Colorado and Iowa. As we await your decision whether data will be shared in Nebraska, we just wanted to re-emphasize that transparency could go a long way to stemming the perception that "The pandemic is over and we can return to business as usual." The recent alarming whistleblower video footage of LTC employees failing to abide by basic PPE requirements suggests that there may be compliance fatigue. Transparency on the scope of the issue will ensure that residents, their families, visitors and staff all understand why ongoing vigilance is necessary.

Information dissemination: We understand that there are email distribution lists and now are requesting permission to have access to same for communication by email with facilities licensed by the state. While we have the rosters online, those only show mailing information. We would like to have the ability to email all licensed facilities if we have independent information to share with same. For example, the Nebraska Department of Education has an Excel spreadsheet of all Superintendents' email addresses that is available to any member of the public who requests it. Similarly, the Nebraska Crime Commission will provide a list of all County Sheriffs and Police Chiefs email addresses alongside their phone and mailing address.

Increased testing: As we have previously expressed, our recent surveys of LTCs show a concerning departure from CDC recommendations. Most recently, the CDC has recommended testing of "all residents and HCP in the nursing home if there is a new confirmed case of COVID19...When one case is detected in a nursing home, there are often other residents and HCP who are infected with SARS-CoV-2 and can continue to spread the infection, even if they are asymptomatic. Testing all residents and HCP as soon as there is a new confirmed case in the facility will identify infected individuals quickly to allow rapid implementation of IPC interventions (e.g., isolation, cohorting, use

of personal protective equipment). When undertaking facility-wide testing, facility leadership should expect to identify multiple asymptomatic residents and HCP with SARS-CoV-2 infection and be prepared to cohort residents and mitigate potential staffing shortage.”¹

Despite this recommendation, our monitoring surveys of facilities reveal this is not occurring. As one example, an LTC administrator of one facility last week told us there had been more than one COVID19 death and testing had been done for only approximately 1/3 of the residents, the bulk of whom tested positive. Clearly, in such a hotspot, it would be appropriate to test every resident and health care professional at that site.

We continue to recommend that all residents of congregate facilities—LTCs, ALFs, DD facilities, and prisons/jails—be tested as a precaution but in the short term we are, at minimum, urging the state to follow the CDC guidelines to test every resident of a facility where a COVID19 diagnosis has already occurred. Testing every resident of, and staff in, a congregate facility is a critical step to prevent outbreaks in congregate facilities.

Recognizing the vulnerability of nursing homes and other congregate facilities for the spread and outbreaks of the Coronavirus, and often as a result of the governor’s executive order, a growing number of states are conducting universal or expanded testing of residents and staff in nursing facilities and/or other congregate facilities.² West Virginia was the first state to require such universal testing and all testing of nursing homes and its universal testing has been completed--22,598 people at 123 nursing homes (8,911 residents and 13,687 staff members). Results of the expanded testing included: identifying an additional 28 facilities with a positive COVID test, affirming that staff were involved in outbreaks, and recognizing most of the people that tested positive were asymptomatic.³

As we discussed on the call, increased testing is an important component to reopening facilities to visitation or relaxing limitations on group dining and recreational activities, since CMS is recommending that can only happen after a facility is free of COVID19 for two weeks.⁴ Without adequate testing prior to reopening the nursing homes, we risk a

¹ <https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-homes-testing.html>

² See Rachel Treisman, National Public Radio, May 15, 2020, “As Nursing Homes Report More COVID-19 Deaths, More Governors Order Universal Testing”, <https://www.npr.org/sections/coronavirus-live-updates/2020/05/15/857279265/as-nursing-homes-report-more-covid-19-deaths-more-governors-order-universal-test>

³ See WSAZ News, May 19, 2020, “Nursing home COVID-19 testing complete in W.Va”, <https://www.wsaz.com/content/news/Nursing-home-COVID-19-testing-complete-in-West-Virginia--570614001.html>

⁴ <https://www.cms.gov/files/document/nursing-home-reopening-recommendations-state-and-local-officials.pdf>

delayed fire of new outbreaks. We hope you will review the CDC recommendations and implement same.

Accessibility of testing: We've been pleased to discover in our statewide survey that some communities have made sure that mobile testing sites—or testing in general—have been thoughtfully conducted to ensure that people with disabilities and those who are medically fragile can receive testing even when they cannot be moved to the testing site. For example, one community described the local hospital reaching out to arrange having a team sent to the LTC to conduct on-site testing. Another facility was able to arrange having the National Guard mobile unit come to their building. Our concern is that many other facilities we spoke with had no plan for how they would handle testing—they told us they didn't have the vehicles or ability to move residents themselves and did not know what would be done to get the population tested as a result. We are hopeful that you will reach out to the mobile units and ask them to proactively contact congregate living facilities (LTCs, ALFs, group homes, etc.) in order to arrange the testing. In addition, we hope you will ask hospitals statewide to similarly contact the congregate living facilities in their area to set up “house calls” when residents cannot be brought to the hospital.

Remdesivir supplies: We understand that there is a very small amount currently shared between multiple hospitals, and that the federal government may soon provide more. In the meantime, we renew our concern about the possibility of medical rationing that we initially shared over ventilator shortages: if there is a shortage of Remdesivir before additional materials arrive, we believe a written protocol that affirms the Office of Civil Rights non-discrimination position would be of assistance to all parties. We understand such a protocol is being developed right now, and look forward to reviewing same when you have completed it.

Long Term Care Ombudsman: We remain willing to collaborate with any entity to expand and improve the monitoring survey work we are doing. If the LTC Ombudsman is currently doing remote / virtual monitoring, we could partner by sharing concerns with particular facilities or dividing monitoring attention between us.

CARES Act funds: Today we learned the state is developing a testing plan to use the federal funding. We are interested in seeing the breakout for what amount of the money is used on testing and what amount is used on related matters.

Visitation: Balancing the desire of some Nebraskans to connect more directly with their family via in person visiting with the ongoing need to maintain social distancing is a difficult problem and we take no position on when and how that should happen, but we are interested in being apprised of the decisions when those are made. Director Green was kind enough to share his efforts to stay in conversation with family and friends of those living at BSDC. We look forward to learning more and similarly urge the state to identify similar ways to involve visitation changes at LTCs, at ALFs, and at other congregate facilities. While BSDC has a robust parents group, there are stakeholders in other, smaller facilities, who need to be consulted as plans develop to lift the restrictions.

Thank you all for your commitment to an ongoing exchange of ideas and concerns. We will continue to compile information from our monitoring work and when we speak with you again on June 4th we will let you know any new information that we've developed. We look forward to continuing to work with you.

Sincerely,

Eric A. Evans, Ph.D.
CEO, Disability Rights Nebraska

Cc: Emily Dodson, Chief of Staff
Tony Green, Director, Division of Developmental Disabilities

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

June 5, 2020
VIA EMAIL

CEO Dannette Smith
Nebraska Department of Health and Human Services
301 Centennial Mall South
Lincoln NE 68509

Dear Ms. Smith:

We're sorry we were unable to meet as planned with you or other DHHS leadership yesterday for our scheduled call. In order to make our next call as constructive as possible, I wanted to provide you with the additional questions and concerns we are hoping to address with you. (The topics in my letter dated May 29th are also awaiting responses.)

Lincoln Regional Center outbreak: Calls from clients at LRC and news reports are concerning. We'd like to request more information about the following:

- Were the staff and resident who tested positive showing symptoms or were they asymptomatic prior to the testing?
- What is the current staffing level for each building at LRC?
- Are steps being taken to test every resident and staff member at LRC?
- What steps are being taken to isolate individuals while continuing to provide therapeutic support?

Beatrice State Development Center: The news about LRC raises the spectre of a similar outbreak in Beatrice. Has BSDC yet begun testing of all residents and staff? If not, is there an immediate plan to begin such testing?

Long Term Care center testing expansion: As I pointed out in my last letter, testing all residents of LTCs is recommended by the CDC if there is a single outbreak. As we continue to conduct monitoring calls and interview staff and laypeople in LTCs, we are hearing concerns about the lack of testing. For example, one facility had a staff member and one resident test positive, but they had to rely on their private contract through their corporate headquarters to accomplish in-home testing of the remaining population. The administrator told us "I don't know why I've had to fight and beg for testing. We've known this virus targets the elderly from day one. It's almost as if no one in the government cares even though it's June and this isn't a mystery anymore."

Long Term Care center inspections: We note with grave concern that Nebraska is trailing far behind the country in inspecting and reporting on our nursing homes.

According to the data released yesterday, Nebraska is 39th in the country for percent of nursing homes surveyed—with only 24.4% of the homes completed.¹ Sister states Colorado, Nevada and North Dakota have surveyed 100% of their nursing homes, and most of our peers have at least completed well over half of their surveys. What steps is DHHS taking to complete the remaining surveys and what is the timeline for completing same?

Remdesivir rationing policy: We have reviewed the DHHS Health Alert Network Advisory dated 6-2-20 regarding the limited supply of Remdesivir. We note with concern the recommendation that Remdesivir be limited to “patients with reasonable functional status.” What definition of “reasonable functional status” is being used by DHHS? Across different medical situations, this phrase has explicitly been used to exclude people with significant disabilities—for example, sometimes patients who need help performing basic tasks during the day. We previously expressed our concerns about rationing policies excluding people with criteria such as this violate federal law and recent OCR guidance. We request additional information about the intended definition of this phrase and—if it is in fact nondiscriminatory in definition—immediate clarification of same to the medical community by follow-up bulletin.

TestNebraska accessibility: We are hearing an increasing chorus across Nebraska with frustration on the lack of accessibility in the TestNebraska rollout. I am aware the Governor has indicated there will soon be a plan forthcoming soon for LTCs: when will those plans be made public? Beyond the LTCs, though, the state has not made provision for people who cannot drive to a test location because they are elderly, medically fragile, blind or low vision, or simply lacking a vehicle. What plans are in place to make TestNebraska accessible to all Nebraskans?

Hopefully, outlining these questions in advance will permit our next call to have robust information and answers. As a reminder, we await the response on the issues outlined in my May 29th letter including:

- Whether the state will provide LTC data transparency
- Whether the state will provide us with the email contact for licensed facilities
- Whether increased testing of LTC residents is in progress
- How CARES Act funds are being allocated
- Visitation policy developments

We look forward to rescheduling our meeting as soon as possible.

¹ <https://theconsumervoice.org/uploads/files/issues/20Nursing20Home20COVID-1920Data-508C.pdf>

Sincerely,

Eric A. Evans, Ph.D.
CEO, Disability Rights Nebraska

Cc: Emily Dodson, Chief of Staff
Tony Green, Director, Division of Developmental Disabilities