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JUSTICE THROUGH COMMUNITY POWER

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To the New York City Council, Committee on Hospitals
Oversight Hearing Examining the City's Support of NYC Hospitals During the COVID-19 Pandemic (November 5, 2020)

People with disabilities of all ages, races, genders, sexual orientations, and socioeconomic backgrounds, are among the most threatened by COVID-19. With City cases on a downward trajectory – at least for now – this is the time to correct the mistakes made earlier this year, and to improve the care given to people with disabilities, before a potentially devastating second wave hits.

I. Background

Approximately one million New Yorkers self-identify as people with disabilities.[1] In some instances, simply having a disability increases the threat of COVID-19.[2] In addition, many with disabilities have underlying conditions which are known to increase the risk of contracting COVID-19.[3] In fact, adults with disabilities are three times more likely than those without disabilities to have heart disease, stroke, diabetes, or cancer.[4] These statistics are even more troubling for Black people since 14 percent of working-age African Americans have a disability, compared with 11 percent of non-Hispanic white people.[5] Moreover, COVID-19 has been most devastating to people belonging to racial minorities, as Latino and African Americans are three times more likely to become infected than white people.[6]

[1] https://www.nychealthandhospitals.org/new-york-city-council-oversight-hearing-the-delivery-of-culturally-competent-equitable-health-care-services-in-new-york-city-hospitals/.
[2] https://www.thecity.nyc/2020/8/5/21356516/homes-for-people-with-disabilities-isolate-covid ("Emerging research suggests people with developmental disabilities are far more vulnerable to COVID-19 than the general population.").
[3] https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html.
[4] *Id*.
[5] https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf.
[6] https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-africanamericans-cdc-data.html.

II. Expected Losses to Hospitals through 2021

New York State hospitals anticipate losing $25 billion through April 2021.[7] Notably, public City hospitals are already struggling – much more so than their private counterparts – and they bear most of the weight of caring for poor and working-class New Yorkers.[8] Critically, the hospital services that should be most protected are those supporting the most vulnerable populations, including people with disabilities.

III. Issues Affecting People with Disabilities Seeking Medical Care at City Hospitals During the First Wave of the COVID-19 Pandemic and Recommendations for Change

- **Threat of Rationing of Medical Care for People with Disabilities**

At the peak of the first wave, medical resource scarcity was a significant concern. Other parts of the world had already begun medical rationing.[9] And for people with disabilities, who often need higher levels of care than people without disabilities, the concern was that medical providers would make determinations to care for others less needy over them. To aid medical providers in making such determinations, New York needs clear and expansive "crisis standards of care" (CSC).[10]

Currently, New York's CSC, which was enacted in 2015, covers only the narrow issue of ventilator allocation, and does so in a way that's deeply troubling for people with disabilities.[11] Incredibly, the existing ventilator guidelines indicate that people with disabilities using a ventilator in everyday life could, when seeking acute care services during a ventilator scarcity crisis, have their ventilator removed and given to a person with a higher likelihood of survival.[12] Making a plea on behalf of people with disabilities, Disability Rights New York, the state's protection and advocacy agency, sent a letter to the Governor

[7] https://pfnyc.org/research/new-york-city-covid-19-economic-impact-update/.
[8] http://www.centernyc.org/urban-matters-2/2020/4/28/covid-19-and-hospital-inequality-why-its-getting-worse-and-how-to-fix-it.
[9] https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html.
[10] https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf (guidance on how to ethically allocate limited resources (i.e., ventilators) during a severe influenza pandemic while saving the most lives.). *See also* https://dredf.org/2020/10/15/people-with-disabilities-not-counted-in-guidance-aimed-at-equitable-allocation-of-a-covid-19-vaccine/ (Crisis standards of care around the country broadly incorporate "comorbidities" that could be used to assign lower prioritization for, or even completely exclude, COVID-19 treatment for patients with "severe or profound intellectual disabilities," "advanced untreatable neuromuscular disease . . . requiring assistance with activities of daily living or requiring chronic ventilatory support," or even just "baseline functional status," such as "loss of reserves in energy, physical ability, cognition and general health.")
[11] *Id.*
[12] https://www.thehastingscenter.org/do-new-york-states-ventilator-allocation-guidelines-place-chronic-ventilator-users-at-risk-clarification-needed/.

to redress these concerns.[13] Additionally, advocates in Kansas filed a complaint regarding that state's CSC, which were modeled after New York's, stating that "regular users of ventilators are afraid to seek medical help when they become ill because ventilator rationing may result in their every-day ventilators being re-allocated to other patients who are deemed a higher priority."[14]

New York was fortunate to avoid a ventilator rationing crisis during the first wave. However, we should not take chances. Now – before the next wave – is the time to pass updated guidelines concerning ventilator usage. The CSC need to be revised to install a clear and non-discriminatory "first come first served" approach to ventilator allocation.[15] Alternatively, given that the New York State Task Force on Life and the Law – the body responsible for the CSC – holds that people with disabilities are not at risk of having their ventilators removed, then the CSC need to be amended immediately to clarify this.[16]

Ventilators, of course, are not the only form of essential care; New York also needs to pass guidelines that assure people with disabilities that they will receive equal access to other respiratory therapies, medications, critical-care beds, and staff during a crisis. Currently, medical providers are without uniform guidance in these matters and are left in the unenviable position of making case-by-case determinations. While these determinations are supposedly "neutral" and "data driven," and intended to produce "objective, unbiased medical decisions," in practice, subjectivity about the quality of life of people with disabilities – based on bias and misinformation – plays a significant role.[17]

- **Overly Restrictive Visitor Policies**

In a frantic effort to control the spread of COVID-19 this past spring, City hospitals instituted strict no-visitor policies.[18] These policies, in some cases, negatively impacted people with disabilities, who often rely on family members, interpreters, and designated caregivers to

[13] *Id.*

[14] https://www.centerforpublicrep.org/wp-content/uploads/2020/03/Kansas-OCR-complaint-3.27.20-final.pdf. *See also* https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf. On March 28, 2020 – one day after the advocates in Kansas filed their complaint – the Office for Civil Rights at the Department of Health and Human Services released a bulletin wherein agency Director Severino stated that "[p]ersons with disabilities…should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism."

[15] https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html.

[16] https://www.thehastingscenter.org/do-new-york-states-ventilator-allocation-guidelines-place-chronic-ventilator-users-at-risk-clarification-needed/.

[17] https://www.nejm.org/doi/10.1056/NEJMp2011359. *See also* https://www.forbes.com/sites/andrewpulrang/2020/04/14/the-disability-community-fights-deadly-discrimination-amid-the-covid-19-pandemic/#1d9206c3309c.

[18] https://thehill.com/blogs/congress-blog/healthcare/508933-people-with-disabilities-need-equal-access-to-medical-care-now.

aid in their effective communication with medical providers.[19] Without the assistance of "visitors," many people with disabilities, including those with intellectual and developmental disabilities, were unable to make informed medical decisions and were thus denied equal access to care.[20] Visitor policies need to be reconsidered, with input from stakeholder communities, to ensure that people with disabilities are not denied equal access to medical care if visitor restrictions again become necessary to control the spread of COVID-19. At a minimum, in order to ensure equal access to medical care, visitor policies need to permit a designated care person – either a family member or professional service provider knowledgeable about the needs of the patient with disabilities – to accompany that patient.[21]

- **Inadequate Communication with People who are Deaf, Hard of Hearing, or DeafBlind, as well as those needing other Language Access Assistance**

Federal, state, and local disability laws require hospitals to provide auxiliary aids and services to people with communication impairments, including those who are Deaf, hard of hearing, or are DeafBlind, thereby ensuring effective communication with medical providers.[22] Communication with people with disabilities must be as effective as communication with people without disabilities.[23] In fact, during the first wave, hospitals, overwhelmed by the crisis, often failed to provide access to American Sign Language (ASL) interpreters or even Video Remote Interpretation (VRI) via computers or smartphones. To make matters worse, masks without see-through plastic mouth portions made lip-reading impossible. These challenges, however, cannot be used as justification for a lower level of medical care.

New York Lawyers for the Public Interest (NYLPI) is aware of a case where a patient who is Deaf was denied appropriate medical care by a City hospital.[24] This person, seeking acute care, was initially denied an ASL interpreter, then denied VRI. As a last resort, this patient took out a pencil and paper, which her medical providers – unbelievably – snatched away, leaving her with no way to communicate.

[19] https://www.npr.org/2020/05/17/857531789/federal-government-asked-to-tell-hospitals-modify-visit-bans.
[20] *Id.*
[21] https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html.
[22] http://adapresentations.org/healthcare/doc/04-23-20/COVID19_Health_Care_and_the_ADA.pdf.
[23] *Id.*
[24] https://thehill.com/blogs/congress-blog/healthcare/508933-people-with-disabilities-need-equal-access-to-medical-care-now.

People requiring language access assistance have also reported issues which have impaired their communication with medical providers.[25] One medical provider from a City hospital stated, "[i]t takes 10 minutes of sitting on the phone to get [a foreign language] interpreter, and that's valuable time when you're inundated." The provider concluded that "the patients that are most mainstream get the best care."[26]

Hospitals need to address these shortcomings now and improve their processes for dealing with them in the future. Among other things, hospitals must ensure that there are sufficient qualified interpreters and auxiliary aids available to meet demands during a crisis, provide staff trainings on how to assess the communication needs of people who are Deaf, hard of hearing, and DeafBlind, and also remind staff of anti-discrimination policies including the obligation to provide people with disabilities with reasonable accommodations.

- **Failure to Make Exceptions to Universal Mask-Wearing Policies**

While universal mask policies are a prevailing method of controlling the spread of COVID-19, certain people with disabilities either cannot wear masks for long periods of time, or at all.[27] Disability laws ensure equal access to health care services, and when necessary, to provide accommodations, even for people with disabilities requiring conflicting accommodations.[28] Accommodations for people with disabilities who cannot wear masks include relying on telemedicine when reasonable and effective, screening and separating patients and/or visitors who may have COVID-19, and having staff use medical-grade personal protective equipment when interacting with people with disabilities who cannot wear masks.

- **Inaccessibility of Telemedicine for Certain People with Disabilities**

Telemedicine, an example of necessity driving innovation, is a valuable tool in the effort to control the spread of COVID-19. Telemedicine has experienced exponential growth since

[25] https://www.propublica.org/article/hospitals-have-left-many-covid19-patients-who-dont-speak-english-alone-confused-and-without-proper-care.
[26] *Id.*
[27] https://www.disabilityrightsca.org/post/covid-19-face-masks-and-people-with-disabilities ("Examples include individuals with developmental or intellectual disabilities, including autistic people, who cannot tolerate masks; people … who cannot independently put on or take off a mask; people with seizure disorders who may be in danger if they experience a seizure while wearing a mask (the mask may obstruct breathing or cause choking); people with lung diseases or breathing difficulties; and people with anxiety disorders who experience panic attacks while wearing masks. Some people use ventilators to support breathing, and may not be able to safely wear a face mask. In addition, some people with disabilities cannot communicate effectively with another person if the other person is wearing a mask. Examples include deaf and hard of hearing people and some people with intellectual, developmental, or processing disabilities.")
[28] https://adata.org/factsheet/health-care-and-ada.

earlier this year. Providing a snapshot of this growth, telehealth visits at NYU Langone Health and the NYU Long Island School of Medicine "jumped from 50 a day to more than 7,000 from March to April [and] ... [b]y this past August, more than 550,000 patients had been screened through a virtual platform."[29]

However, certain people with disabilities are unable to benefit from this health care option.[30] A large percentage of people with disabilities live below the poverty line; without baseline technology devices and broadband internet, the platform is not useful. Certain people with disabilities may not possess the level of technology literacy necessary to utilize telemedicine. Additionally, people with disabilities with communication impairments may not be able use the technology without the assistance of an interpreter on hand. The lack of in-person connection between the medical providers and people with disabilities risks the delivery of a lower level of care.

To address these access barriers, appropriate funding must be allocated to ensure that users possess adequate technology devices and internet services, trainings must be provided to raise technology literacy levels when appropriate, and procedures must be instituted to address the risks of diminished quality of care when treating people with disabilities through telemedicine.

IV. Recommendations

- Encourage the New York State legislature to revise its CSC pertaining to ventilator rationing, clarifying that people with disabilities currently using a ventilator will not be taken off their ventilators when seeking acute care. Additionally, broaden the CSC to assure people with disabilities that they will receive equal access to all other respiratory therapies, medications, critical-care beds, and staff during times of resource scarcity.

[29] https://mhealthintelligence.com/news/nyc-hospitals-create-blueprint-for-covid-19-triage-by-telehealth.

[30] *Id. See also* https://www.mdpi.com/1010-660X/56/9/461/htm ("The advantages of telemedicine in assessing and managing Covid-19 have been highlighted here, but when deciding whether this approach is the right one for an individual patient, it is important to consider the drawbacks. Telehealth is only possible if the patient has literacy in the modality used for delivery and if the internet or phone connection is of reasonable quality. Bandwidth, software or other technical issues may interfere with data transmission and obstruct visual and/or auditory aspects of communication. This problem may be encountered more commonly in rural areas and in socioeconomic disadvantaged environments with limited access to technology. Privacy and confidentiality may also be an issue for patients using equipment in areas frequented by other household members. Use of headphones by the patient may be helpful, but do not guarantee privacy. Persons with barriers to use of technology such as visual or hearing impairments may require in-person visits, although specialized communication platforms can make telecare feasible in some circumstances. Without the in-person encounter, the feeling of a personal connection and establishment of a provider-patient relationship with the key elements of trust and mutual respect is more difficult.")

- Revise City hospital visitor restriction guidelines, with input from disability community stakeholders, to ensure the rights of people with disabilities to equal access to medical care.

- Mandate training for medical providers at City hospitals to recognize implicit bias as it pertains to people with disabilities. Unacknowledged bias has been demonstrated to contribute to worse health outcomes for people with disabilities.[31]

- Encourage the New York State legislature to repeal Article 30-D of the Public Health Law, also known as the Emergency or Disaster Treatment Protection Act, which offers broad protections to hospitals and their executive leadership from civil liability arising from certain acts or omissions resulting in harm during the COVID-19 pandemic, thereby stripping patients and family members of their rights to hold hospitals accountable.

- Allocate appropriate funding and resources to improving the telehealth experience for people with disabilities.

Thank you for the opportunity to testify about the key issues which have negatively impacted access to medical care for people with disabilities during the COVID-19 pandemic. Please feel free to contact me to discuss further.

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About New York Lawyers for the Public Interest
For over 40 years, NYLPI has been a leading civil rights and legal services advocate for New Yorkers marginalized by race, poverty, disability, and immigration status. Through our community lawyering model,

[31] Independence Care System & New York Lawyers for the Public Interest, Breaking down barriers, breaking the silence: Making health care accessible for women with disabilities (2012), p. 7, 15. Available at: https://www.nylpi.org/images/FE/chain234siteType8/site203/client/breakingbarriers.pdf. *See also* ADA National Network, Health Care Access and the ADA: An ADA Knowledge Translation Center Research Brief (2019). Available at: https://adata.org/publication/health-care-access-and-ada *citing* Yee, S., et al., Compounded disparities: Health equity at the intersection of disability, race, and ethnicity, The National Academies of Sciences, Engineering, and Medicine (2016).

we bridge the gap between traditional civil legal services and civil rights, building strength and capacity for both individual solutions and long-term impact. Our work integrates the power of individual representation, impact litigation, organizing, and policy campaigns. Guided by the priorities of our communities, we strive to achieve equality of opportunity and self-determination for people with disabilities, create equal access to health care, ensure immigrant opportunity, secure environmental justice for low-income communities of color, and strengthen local nonprofits.

NYLPI's Disability Justice Program

NYLPI has a long history of fighting for the rights of people with disabilities, including in the area of access to medical care. As a member of a coalition of advocates and City and State civil rights enforcement agencies, NYLPI pursues systemic improvements by connecting with community members to educate them about their rights to accessible medical equipment, accessible facilities, reasonable accommodations, and filing complaints. During the COVID-19 pandemic, NYLPI has reminded various of the large City hospitals of their obligations to provide auxiliary devices and services for people who are Deaf, hard-of-hearing, or Deafblind.