DISABILITY RIGHTS NEW YORK

www.drny.org mail@drny.org 518-432-7861

SUBMISSION OF WRITTEN TESTIMONY FOR THE NEW YORK CITY COUNCIL'S COMMITTEE ON CIVIL AND HUMAN RIGHTS

"Oversight – the New York City Commission on Human Rights' Response to the COVID-19 Pandemic", October 23, 2020

Submitted on behalf of Disability Rights New York by Alison J. Lynch, Staff Attorney, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program

INTRODUCTION

As is the case with other aspects of emergency preparedness, when it comes to this pandemic people with disabilities are often the last to be asked and the first to be impacted. This can also lead to unchecked discrimination against some of our most vulnerable residents.

Disability Rights New York (DRNY) serves as New York State's federally designated Protection and Advocacy (P&A) System. The state-based organizations in the P&A system were created in the 1970s as a result of media coverage at the Willowbrook State School on Staten Island, and work at the state level to protect the rights of individuals with disabilities through legal advocacy. DRNY provides free legal assistance to people with disabilities, as well as engaging in monitoring and investigation of facilities and programs that serve individuals with disabilities. In this capacity, DRNY enforces the rights of people with disabilities through individual and systemic litigation.

When the COVID-19 pandemic hit New York City in March, DRNY immediately recognized that individuals with disabilities would be at distinct disadvantages in many ways, ranging from medical concerns to safe living to disability-based discrimination. Throughout the past seven months, DRNY has worked to provide education, outreach, information and assistance to New Yorkers in need of legal advocacy, advice or referrals. We recognize that other organizations, like the New York City Commission on Human Rights, have been engaged in similar efforts, and want to encourage them to continue working on comprehensive outreach and education.

DRNY is submitting this testimony in order to bring to light several issues facing individuals with disabilities across New York City. The Commission has recognized that the category of disability discrimination is one of its most frequently cited in discrimination and harassment complaints, and this has only increased with the pandemic. It is well-documented that individuals with disabilities have been disproportionately affected by COVID-19.[1] That does

[1] World Health Organization. Disability considerations during the COVID-19 outbreak; https://www.who.int/docs/default-source/inaugural-who-partners-forum/english-covid-19-disability-briefing.pdf?sfvrsn=8a1aa727_1&download=true (last visited October 28, 2020).

not just mean that they are at higher risk of having complications. It means, in reality, that they are at higher risk of contracting it, not being able to properly quarantine, and not receiving the same standard of care once they do contract it. This may be due to their living situation, their ability to seek and receive adequate healthcare, or the availability of resources to assist them during a quarantine or illness. These deficiencies in resources and support can compound disability-related harassment and discrimination, and necessitates a greater all-hands response to combat these situations.

For these reasons, DRNY calls upon the Commission to continue working on its robust and preemptive education and outreach efforts in the disability community, as well as within organizations and citywide services that may come into contact with individuals with disabilities during this unstable time in New York City.

While there are a wide variety of issues unique to the disability community in light of COVID-19, DRNY is submitting the following for Committee review:

1. Congregate Care

DRNY received a number of calls from individuals in congregate settings who were concerned about COVID-19, and discrimination resulting from their living situation. Congregate living can pose a unique set of challenges, particularly for individuals with disabilities. This type of housing includes adult homes, nursing homes, group homes, homeless shelters and other group community residences. DRNY received calls regarding many different types of congregate care, and the concerns ranged from ability to quarantine, availability of testing and PPE, discrimination and harassment by staff, and difficulty surrounding discharge and community-based services. We are choosing to highlight only a few of the many issues we encountered in congregate settings.

Homeless Shelters

Many of the most troubling calls, and the types of concerns that many New Yorkers have become familiar with, involve the New York City shelter system. As the COVID-19 crisis continues to grip the city, few are at greater risk than families and individuals experiencing homelessness. Homeless New Yorkers often have nowhere to self-quarantine, cannot practice social distancing, and those on the streets lack even regular access to a sink with running water and soap to wash their hands. They are also statistically far more likely to have a "disabling condition"; one study found 67% of single individuals experiencing homeless were people with disabilities.[2] Furthermore, homeless New Yorkers are also far more likely to have the types of underlying medical conditions that result in high mortality rates from COVID-19.[3] This is still true almost seven months after the pandemic took hold in New York City. In fact, one study

[2] Coalition for the Homeless. State of the Homeless 2020; https://www.coalitionforthehomeless.org/state-of-the-homeless-2020/
[3] *Id.*

calculated that the COVID mortality rate for sheltered homeless New Yorkers was 403 deaths per 100,000 people. This is 78% higher than the rate for New York City at large.[4]

When the pandemic hit, these residents were forced to quarantine in shelters without PPE for residents or staff, without room to social distance, and without access to testing. Additionally, many reported a lack of information and education about what was happening, at a time when this education was so important to our rapidly evolving understanding of this disease. Many individuals experiencing homelessness also had difficulty accessing medical care for underlying conditions that made them more susceptible to serious complications from COVID-19. Hospitals did not have the space to admit them, and they were forced to return to the shelter or the street while maintaining sometimes debilitating medical or mental health conditions.

DRNY received several calls from individuals forced to transfer themselves between a hospital emergency room and a shelter several times, with no overlap of services to help them medically or to ensure they were safely quarantined after returning from a hospital. In one particularly problematic case, a DRNY client experiencing homeless, who is also a wheelchair user, was forced to wheel himself between a city homeless shelter and a hospital over a mile away, and back to the shelter on three separate occasions after he attempted to seek treatment for an underlying medical condition. He was never admitted or given any type of assistance in transporting himself, either by hospital or shelter staff. Finally, during the sixth time he had made this journey, his wheelchair broke and he was forced to crawl the quarter mile back to the shelter, across a busy highway and over a bridge. Only after involvement from DRNY, city officials and shelter staff was this individual given the proper hospital care required, provided with a new wheelchair, and moved to a more appropriate rehabilitation setting to address ongoing health concerns. This client's story is not unique, and has been echoed throughout the shelter system as responses to calls for assistance went unheard.

The move to house homeless individuals in hotels to create safe quarantine space and free up shelter beds came weeks after many in shelters were already sick or exposed. While the program had good intentions, there remained issues with appropriate discharge and timely care being provided to those quarantined in hotels. Some individuals reported to DRNY that they were not being given routine medication for medical and psychiatric treatment, while others stated they were not provided with PPE and saw staff without PPE. Additionally, there seemed to be a great deal of confusion surrounding discharge from the hotel after an initial quarantine; callers to DRNY reported that they had nowhere to go after being told they must leave the hotel after 14 days, despite not having spoken with city or shelter staff about discharge planning. One client stated that he left the hotel and was back on the street, almost immediately re-exposing himself to COVID-19 and, in theory, qualifying himself for another 14-day stay at a hotel to quarantine.

The failure to prioritize safe spaces to quarantine, provide widespread testing availability and PPE created a detrimental situation for many of our clients living in congregate settings, leading to an increased risk of discrimination and harassment. The Commission should work on

[4] Coalition for the Homeless. Age-Adjusted Mortality Rate for Sheltered Homeless New Yorkers; https://www.coalitionforthehomeless.org/age-adjusted-mortality-rate-for-sheltered-homeless-new-yorkers/

more robust outreach strategies to shelters, hotels and other congregate settings to bring education and awareness to their role, and the complaint process, since many in these settings have frequently complained of discrimination. There is still a great deal of unrest for homeless New Yorkers being shuttled between various hotels and shelters to appease neighborhoods that are fed up with their presence. A new wave of COVID-19 could very easily put many individuals at risk of infection back on the streets with no services.

Group Homes

Another example of a type of congregate living that became potentially dangerous for New Yorkers with disabilities is the group home system. While no state agency has yet released public information on the infection and fatality rates for people I/DD residing in congregate settings, records obtained by DRNY reveal there have been 471 COVID-related deaths across at least 337 certified residences, and just under half of the deaths reported to the Justice Center occurred in the five boroughs of New York City.

What is critical about these numbers, and highlights the unique dangers faced by individuals with I/DD is that people residing in OPWDD operated and certified settings died from COVID-19 at a notably higher rate than the general population. A recent study found the case-fatality and mortality rates were markedly higher for people with I/DD than the general population of New York State: 15.0% compared to 7.9% for case fatality; 1,175 per 100,000 compared to 151 per 100,000 for mortality rates.[5]

What is especially troubling is that many of these deaths were unnecessary. The state and city were aware this population was at grave risk but did nothing to protect them. On March 25, 2020, The Office for People with Developmental Disabilities (OPWDD) issued safety guidance advising that when any individual residing in an OPWDD-certified facility is suspected of having COVID-19, either the sick individual should wear a facemask in the presence of others, or staff should wear a mask when in the same room as that individual.[6] The same guidance directed that staff should also wear a disposable facemask and gloves when having any contact with that individual's bodily fluids.[7] Despite this clear acknowledgment of the vulnerability of people with I/DD in congregate settings, both the state and the city refused to give them equal priority with nursing facilities for PPE and containment resources.

Indeed, group homes serving people with I/DD are markedly similar to nursing facilities in all the ways that matter in the face of a highly contagious virus. Direct Service Professionals (DSPs) provide intimate care for residents throughout the day, including physical assistance with washing, toileting, dressing, and eating. It is not possible for DSPs to maintain 6 feet of separation from residents. Many individuals with I/DD, like those in other congregate settings,

[5] Scott D. Landes et al. COVID-19 Outcomes among People with Intellectual and Developmental Disability Living in Residential Group Homes in New York State, Disability and Health Journal (2020). DOI: 10.1016/j.dhjo.2020.100969; https://www.sciencedirect.com/science/article/pii/S193665742030100X.
[6] *See* OPWDD, Staff Guidance for the Management of Coronavirus (COVID-19) in Facilities or Programs Operated and/or Certified by OPWDD (March 25, 2020) http://aabr.org/wp-content/uploads/2020/03/3.25.2020-staffing-guidance-document_final.pdf (last visited August 7, 2020).
[7] *Id.*

live in close proximity to one another and cannot adhere to prevention protocols. Many people with ID/DD have weakened immune systems that require additional treatment time and medical resources if they become sick.

On March 20, 2020, the NYC Department of Health and Mental Hygiene advised that priority recipients for PPE would include only hospitals, emergency medical services, nursing facilities, and dialysis centers. Although this list was updated in April 2020 to include group homes licensed by OPWDD, in practice, agencies operating group homes continued to struggle to obtain PPE. For example, staff at one New York City agency reported to DRNY that they felt they were "going in circles" in their requests for assistance obtaining PPE from NYC Emergency Management, the New York City Emergency Operations Center, the New York State Department of Health, and OPWDD. After making multiple requests for PPE in March and April, and receiving no assistance, the agency focused its efforts on obtaining PPE independently. As of May 5, the agency reported spending over $16,000 obtaining PPE on the open market. Another agency reported that it eventually received PPE from the NYC Mayor's Office approximately 7 weeks after it placed a request. The situation was particularly untenable for smaller OPWDD-certified agencies, which have far less purchasing power than entities with the means to purchase PPE in bulk.

In addition, although agencies serving individuals with ID/DD were reporting dire PPE shortages, they went for weeks without guidance from the State or City on this issue. It was only on April 2 that DOH Issued a Health Advisory addressing how facilities might address critical PPE shortages through limited re-use of PPE.[8] DOH noted it had become aware of instances of health care providers using "dubious means" to attempt to disinfect facemasks and respirators, such as putting them in the dishwasher. Four days later on April 6, OPWDD applied the DOH guidance to its certified residential settings without any modifications.[9]

The health and safety of people with I/DD in congregate settings was also put at greater risk by COVID-19 testing policies. The NYS DOH failed to institute or mandate testing of individuals and staff at OPWDD-certified settings, placing individuals with I/DD, and the staff who care for them, at significantly higher risk. Staff seeking testing found it nearly impossible to find, particularly in April when the virus was peaking. Direct Support Professionals and residents with I/DD were given no priority over the general population.

Many of these disparities continue to the present day. This continues to place residents with I/DD and staff at a greater and unnecessary risk of exposure.

Inpatient Psychiatric Centers

[8] NYS DOH, Health Advisory: Options when Personal Protective Equipment (PPE) is in Short Supply or Not Available (April 2, 2020), *available at* https://coronavirus.health.ny.gov/system/files/documents/2020/04/doh_covid19-_ppeshortages_040220.pdf (last visited August 7, 2020).
[9] OPWDD, Memo regarding COVID-19 PPE Shortages (April 6, 2020), *available at* https://opwdd.ny.gov/system/files/documents/2020/04/4.6.2020-opwdd-memo-regarding-covid19-ppeshortage_0.pdf (last visited August 7, 2020).

DRNY also closely followed changes made to inpatient psychiatric units during the initial response to the pandemic. This included repurposing hundreds of beds on psychiatric units to prepare for COVID-19 patients, without strategies in place to ensure that those discharged early would continue to receive the same level of psychiatric care. These bed closures led to somewhat of a crisis situation in mental health care. Treatment became, and continues to be, harder for many to find just when the pandemic has created and driven a higher demand for services.

When the pandemic began to take hold in New York, psychiatric bed space was viewed as an easy source of overflow beds for incoming COVID-19 patients. While DRNY recognizes the importance of ensuring beds for those needing COVID treatment, it left many psychiatric units forced to make dramatic changes that included discharge of patients who otherwise may not have been deemed discharge-ready.

Recently, the state Office of Mental Health (OMH) estimated that 400 psychiatric beds remain closed around New York State, but most of the closures are in New York City. OMH has stated that it expects all of these beds to be reintegrated back into psychiatric units eventually, but there has been no timeframe or plan shared with the public, or with relevant oversight groups like DRNY and its partners who are frequently tasked with advocating for individuals in this system. Initially, non-COVID hospitalizations slowed at the onset of the pandemic, but according to some hospitals, they are back to pre-pandemic levels in recent weeks. This means that the already-crowded New York mental health system is short even more beds than they were just seven months ago.

Part of the reason that hospitals may be closing behavioral health beds is to comply with Governor Cuomo's order that hospitals have a surge plan in place in case of a second wave of COVID-19[10]; however, the order does not mandate a certain number, or type, of beds remain closed for treatment. Hospitals have made a specific choice to close or repurpose behavioral health beds.

The nonprofit Treatment Advocacy Center, in reviewing the numbers of beds closed in New York since March, and the length of the average stay, has estimated that 14,000 psychiatric admissions across the state were not made – all people who may otherwise have needed inpatient hospital treatment but were not ultimately able to get it.

Anecdotally, it has been reported by several sources that a Brooklyn hospital closed two units with 50 beds total in late March in order to convert beds for COVID-19 patients. When the announcement to close these beds was initially made, several patients who were still potentially a danger to themselves or others were discharged, rather than transferred for continued hospital-level care. Additionally, some units in a Manhattan hospital that typically sees around 1500 patients a year remain closed. This puts pressure on other nearby hospitals to deal with mental health admissions, creating just the type of cascading effect that is most dangerous for a potential second wave – hospitals with a higher census unable to appropriately reallocate beds for a new wave of COVID-19 patients.

[10] Information on Novel Coronavirus; https://www.governor.ny.gov/news/amid-ongoing-covid-19-pandemic-governor-cuomo-outlines-additional-guidelines-when-regions-can (last visited October 28, 2020).

Additionally, DRNY received information from partner organizations and our own monitoring and investigations that staff numbers at psychiatric facilities were difficult to maintain, since many staff needed to quarantine or recover from the virus. This is a concern to DRNY and other mental health advocates, as inadequate staffing on inpatient psychiatric units can lead to a higher number of physical and chemical restraint incidents, due to staff feeling overwhelmed and unable to properly de-escalate situations that can occur on a unit.

Another concern flagged by DRNY through monitoring during the first few months of the pandemic was the possibility that individuals in psychiatric units would become increasingly disconnected with family, friends and other means of support in the community. Often, psychiatric centers were not able to seamlessly transition into halting in-person visitation and moving to video visitation options. This left many residents unable to get in touch with people in the community at a time when these communications were particularly important.

The failure to appropriately plan for hospital surges and recognize the need for appropriate discharge and community mental health care has dramatically impacted New Yorkers who were, or continue to be, in need of psychiatric treatment. The Commission could work on outreach to individuals with mental illness, especially those discharged who may not have a place to go for services and may have greater need for protections against harassment.

New York State's emergency preparedness protocols failed to prioritize the needs of people who reside in congregate care settings. Excluding congregate settings from the facilities prioritized for PPE and testing put both residents and providers at high risk of contracting, spreading, and dying from COVID-19. All future emergency preparedness planning must include realistic and informed strategies to insure the safety of people with disabilities, and all emergency planning at the state and local level must be guided by the voices and needs of people with disabilities.

2. Community Medical and Mental Health Care

DRNY also received many calls about care outside of hospitals. While there were a number of issues raised, there are several in particular, outlined here, that highlight the unique difficulty for people with disabilities in the community.

Community Mental Health Services

While there were, and remain, obvious challenges for individuals with mental illness seeking inpatient treatment, there continue to be barriers for those outside the hospital to receive consistent treatment, as well.

Many community mental health programs were shuttered when the pandemic began in New York City, leaving individuals who would routinely receive care and services with nowhere to go. Many workers, like those in congregate care facilities, complained that there was no PPE or prioritized testing, so they felt unsafe continuing to go into work. There were not strong protections provided for these frontline workers, leading to a decrease in available services.

These workers make it possible for individuals with severe mental illness to live successfully in the community. When clients of these programs have nowhere to go, they may be forced to go back into the overcrowded psychiatric hospital unit, or may be at an increased risk of encountering harassment due to a potentially decompensating mental state.

Many organizations that provide such invaluable services are already stretched thin and may not be able to survive the economic fallout of the pandemic, especially as populations in need surge and treatment protocols shift. The Commission should consider advocating for this population, at greater risk of discrimination and harassment, and work to coordinate city and state resources to protecting them, and the clients they serve.

Interactions with Medical Providers

COVID-19 also dramatically changed how individuals with disabilities were able to interact with medical providers, both in routine examinations and in more serious circumstances where hospitalization was required. Policies meant to ensure safety failed to take the needs of individuals with disabilities into account, and resulted in discriminatory practices for individuals with communication differences.

One concern that DRNY has flagged through multiple accounts from callers is the policy regarding hospital support for people with I/DD. On March 18, 2020, DOH issued a policy suspending all hospital visitations statewide.[11] It was not until April 10 that a revised policy was issued to clarify that patients with I/DD may require a support person as an essential component of their care and must be allowed a support person if needed.[12] Several of the agencies DRNY spoke with explained that hospitals prohibited residential staff support for individuals with ID/DD before the revised policy was issued; residential support staff were refused entry. This left individuals with complex needs and limited communications skills alone at a time when hospitals and hospital staff were overwhelmed with COVID patients and ill equipped to bridge very critical communication barriers.

3. Rationing of Medical Equipment and Resources

Another issue that must be addressed in advance of another widespread surge in New York City and any subsequent public health crisis is the status of state guidelines published by the Department of Health in 2015, which create the potential for daily ventilator users to have their ventilators removed from their person and rationed if they enter a hospital seeking acute care when ventilators are in short supply. DRNY received calls from many daily ventilators users who feared for their lives during the dark days when it was not clear if city hospitals would have

[11] NYS DOH, Health Advisory: COVID-19 Guidance for Hospital Operators Regarding Visitation (March 18, 2020), *available at* https://coronavirus.health.ny.gov/system/files/documents/2020/03/covid19-hospital-visitation-guidance-3.18.20.pdf (last visited August 7, 2020).
[12] NYS DOH, Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation (April 10, 2020), *available at* https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf (last visited August 7, 2020).

enough ventilators available. This dangerous policy decision motivated DRNY and partner NCLEJ to recently file a federal lawsuit challenging these discriminatory guidelines.

RECOMMENDATIONS

DRNY recommends, as many others have throughout these past few months, that preparation for multiple waves of this pandemic is paramount. It is our position that, in making these preparations and reviewing what happened in the early stages of the pandemic, individuals with disabilities who are most at risk should be prioritized in any planning, guidances and recommendations that could impact their care both in congregate settings and in the community. For many clients that we served, this was not the case, and disability-related coordination of care, services and support seemed like an afterthought.

Robust and timely preparation for what appears to be an inevitable next wave of COVID-19 should include outreach, education and proactive engagement with members of disenfranchised groups, as well as those in close contact, either to ensure that they understand potential rights violations, and also to ensure that family, friends and advocates have a clear understanding of how to engage with the Commission on behalf of or alongside individuals with disabilities who may be unaware of the protections offered.

Additionally, we recognize that race, gender, class, immigration status and other identities can also have a tremendous intersectional impact for individuals with disabilities, and the confluence of these factors has never been clearer. This recognition serves as an undercurrent to everything discussed in this submission, and in the work that DRNY does for its clients.

CONCLUSION

DRNY is grateful to the Committee for the opportunity to provide oral and written testimony on these critical matters. We appreciate the Chair's recognition of the work that needs to be done, and look forward to ongoing participation in these conversations as we move forward in our advocacy efforts in light of COVID-19.