Mayor's Office for
People with Disabilities

**Testimony of Christina Curry, Commissioner,**
**NYC Mayor's Office for People with Disabilities**

**Oversight: Evaluating the Current State of Health Care Access for Patients with Disabilities - before the New York City Council Committees on Hospitals and on Mental Health, Disabilities and Addiction**

April 21, 2025

Good afternoon, Chair Narcisse, Chair Lee and members of the Committee on Hospitals and Committee on Mental Health, Disabilities and Addiction.

Thank you for holding this important hearing. I'm Christina Curry, Commissioner of the Mayor's Office for People with Disabilities (MOPD). I'm joined by Emily Sweet, General Counsel at MOPD, as well as Julie Friesen, Deputy Commissioner of Administration at the NYC Department of Health and Mental Hygiene (DOHMH), Ivelesse Mendez-Justiniano, Chief Diversity, Equity & Inclusion Officer at NYC Health + Hospitals (H+H) and Manuel Saez, Vice President of Facilities at H+H.

I come to this work not only as a public servant, but also as a member of the disability community.

At MOPD, our vision is for all City programs and services—including healthcare—to be accessible and equitable for the nearly one million New Yorkers living with disabilities. We know that for many in our community, accessing health care remains a challenge. These challenges range from physically inaccessible exam rooms and diagnostic equipment to communication barriers and a lack of culturally competent care.

We appreciate that our City partners at Health + Hospitals and the Department of Health and Mental Hygiene are actively engaging on these issues. We've seen meaningful steps to address facility access, integrate ASL interpretation into appointments, expand digital accessibility for

telehealth platforms, and develop disability awareness trainings—all of which are still in progress.

We also recognize that the lived experience of many New Yorkers with disabilities reveals where the gaps remain. They point to a broader need for sustained attention and systemic improvement.

MOPD stands ready to support our agency partners in advancing solutions. Whether through technical assistance or ongoing trainings, we are committed to serving as a bridge between government systems and the disability community, ensuring that people with disabilities are not only included in conversations about healthcare, but centered in how we design and deliver care across the city.

Let me close with a reminder of a powerful motto from the disability community: ***"Nothing about us without us."***

Thank you again for your leadership on this important issue. On behalf of myself and my colleagues from NYC Health + Hospitals and the Department of Health and Mental Hygiene, we welcome your questions and look forward to our continued partnership.

UNITED AMBULETTE COALITION
*Preserving Your Lifeline to Critical Care*

**RE: Exemption from Double Parking and Bus Lane Violations**

April 21, 2025

Honorable Members of the New York City Council:

Thank you for the opportunity to meet with you today. My name is Neal Kalish, and I represent the United Ambulette Coalition, an industry association representing NYC's ambulette providers, seeking a positive construct and resolution for issues impacting upon our ability to provide quality care and service.

**I'm here today seeking the City Council's introduction and support for legislation exempting ambulette providers from double parking and bus lane violations now being issued with alarming frequency**. Our understanding is language is being drafted exempting ambulettes from these violations, and as an interim measure a letter to NYC DOT requesting leniency for ambulettes is being routed to council members for sign on. I believe Chair Lee's office has taken on this initiative, and we are truly appreciative.

**Briefly, as background**, Ambulettes ensure access for New York City's most vulnerable population; the poor, sick, handicapped and elderly Medicaid enrollee traveling to medically necessary care and treatments, such as dialysis. For the population we serve, transportation is a critical obstacle to receiving preventative care and treatment... it is not a convenience—it is a lifeline. We go door to door escorting wheelchair bound, and ambulatory clients. Our drivers travel in some of the most challenging neighborhoods in the nation. We carry wheelchair bound client residing in non-elevator equipped buildings up and down stairwells. The work we perform is time consuming and labor intensive.

**As an illustration of the service we provide**, we work unfailingly, during blizzards, during Hurricane Sandy, and throughout the height of the COVID-19 pandemic, when the city was at a standstill—subways suspended, bus service halted and livery services offline—ambulette providers continued to operate. We did so despite tremendous risk and financial hardship because we understood our responsibility to the patients and the dialysis clinics and New York City hospitals who depend on us.

**Today, that same commitment is being punished.**
Bus Lane and Double-Parking violation are triggered automatically by MTA Bus video cameras. These fines are progressive: a first offense is $50, then $100, $150, and up. We now routinely see penalties of $200, $250 or more per vehicle. The expansion of the MTA's enforcement program has created the problem, and it is spiraling upward uncontrolled.

**Please consider:**

- Curbside parking near medical offices, dialysis units, or patients' homes is rarely available. And many facilities and passenger /patient residences adjoin bus lanes, that we need to enter to safely load and unload passengers.
- Our drivers must remain in proximity to the medical facility or the Medicaid enrollee's residence to assist the passenger who is wheelchair-bound or ambulatory but physically challenged—many are frail, elderly, or recovering from exhaustive treatments.
- Loading and unloading safely takes time and space. Circling the block to hunt for a rarely available curbside space is not an option.

**This is not a new challenge**—we have always had to double park in certain circumstances. What is new is the overwhelming volume of tickets now being issued by automated video camera systems without context or discretion.

If this issue is not addressed legislatively, it will threaten our ability to continue serving the Medicaid population. These financial penalties are unsustainable. Ambulette providers are Medicaid-funded small businesses and operate on thin margins. Absorbing thousands of dollars in monthly violations is not feasible.

Based on the essential service we provide, we were granted an exemption from congestion pricing, as an example, and now we require an exemption from double parking and bus lane violations. This is an exemption granted to the MTA's Access-A-Ride program, and ambulette providers require this same exemption.

Our understanding is that legislation is in development. We are deeply grateful for this progress and urge the Council to act swiftly.

We thank you for your time and urge your support on this issue.

Sincerely,

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**Testimony of Evan Yankey, Advocacy Director,**
**before the New York City Council hearing on**
**Oversight—Evaluating the Current State of Health Care Access for Patients with Disabilities**
April 21, 2025

My name is Evan Yankey, Advocacy Director for the Brooklyn Center for Independence of the Disabled (BCID), a disability-led independent living center promoting the rights of New Yorkers to live in the community since 1956.

We are pleased that this committee is holding this hearing today and giving the current state of healthcare access for patients with disabilities the consideration it deserves. The U.S. Census estimates that about one in five Americans have a disability, which would mean that 1.7 million New Yorkers have one or multiple disabilities.

People with disabilities in our city's healthcare system face many barriers to equal access, support and care. While some of them, including the MTA and the City's shortfall in providing fully accessible transportation, fall outside the immediate purview of your committees, the Council as a whole can play a crucial role in advocating for them.

These committees alone can investigate, advocate for and propose legislation that will lead to better health outcomes for disabled people. We urge the Council to:

- **Pass legislation that will require an independent accessibility review of NYC Health + Hospitals**, including physical and communications barriers, with additional requirements that sets specific targets for the elimination of these barriers.

  Currently, New Yorkers with disabilities, many of whom depend on NYC Health + Hospitals, face:

  – *physical barriers*, including poorly accessible buildings, inaccessible exam tables and other devices.
  – *communications barriers* including sketchy availability of American Sign Language interpretation; limited availability of Plain-Language and Easy-Read formats; and inaccessible forms and websites.
  – *Inflexible office procedures* that don't take into account their disabilities
  – *poorly trained doctors, other medical personnel, and other Health + Hospitals employees* who discriminate against them because of their disabilities, in part because of inadequate training.

None of these barriers are immutable. An independent review would start NYC Health + Hospitals on the way to real accessibility for disabled New Yorkers, especially if there are goals set to change the situation.

- **As a part of the independent review or separately, require the City to hire an independent assessor to examine Health + Hospital facilities for diagnostic equipment** that complies with the federal Access Board's accessibility standards for medical diagnostic equipment as well as buildings that comply with the Americans with Disabilities Act, the Rehabilitation Act, and the Architectural Barriers Act.
- **Pass legislation and funding designated for the training of NYC Health + Hospitals staff in regular, in-depth training led by disability organizations.** For example, VISIONS/Services for the Blind and Visually Impaired has developed a comprehensive training program that is appropriate for all disabilities. Many patients with disabilities we speak to report a mix of negative interactions with healthcare providers that include rudeness and refusal of service, as well as a general lack of disability competence. Training and oversight can reverse that disturbing situation.
- **Pass legislation to establish an Office of the Patient Advocate**, which would make certain that these reviews and changes receive appropriate follow-through. The office would also accept complaints from patients served by NYC Health + Hospitals, track them, and make recommendations for specific and systematic accessibility improvements to city officials.

**Whether or not legislation moves forward, the Council itself should use this hearing to launch its own investigation of these barriers**, including at private institutions, with an eye toward more rapidly ensuring that all city health providers meet the requirements of New York City Human Rights Law, the Americans with Disabilities Act (ADA) and other laws.

**Other priorities**

Your committees and the Council can play a significant role on other concerns that are crucial to our community, including:

- **Opposing rules that would prevent people with disabilities or anyone else from using masks.** Disabled people in particular may face barriers to care in spaces where mask-wearing is not implemented or where mask-wearing is criminalized, as is proposed in "mask-ban" legislation currently supported by Governor Hochul. Masks protect people with disabilities and others from flu, COVID, and RSV, and their usage in medical spaces make those spaces safer for patients and medical providers alike. **Laws that criminalize their use will subject people with disabilities to undue scrutiny and a risk of negative interactions with police, first responders, and vigilante citizens opposed to mask-wearing.** We hope that the committee can support an ongoing mask-supportive environment in health and medical spaces.
- **Support smarter responses to mental health emergencies by implementing the peer support proposals championed by Correct Crisis Intervention Today-NYC this year.**

- **Work to preserve remote and telehealth options for people receiving supports and care.** Everyone benefits from being able to choose the format of their care, and the travel barriers people with disabilities often face make remote interactions a good option for some.
- **Oppose the closure or reduction of services in safety-net hospitals.** We hardly need a return to the 1970s, when the City engaged in a reduction of vital services. People with disabilities are often poor, and many have faced cuts in service as safety-net hospitals in low-income communities have attempted to close. It is critical for the City Council to support efforts to make sure health services are available in all communities, and that providers cannot easily pull out of communities that are low-income.

Finally, we ask this committee to be attentive to the threats happening at a federal level to healthcare in New York. Congress has proposed devastating cuts to Medicaid that would hurt New Yorkers with disabilities and others, and we urge you to resist these cuts and to prepare our city to commit to continuation of eligibility and care if these cuts go through.

We also encourage you to take a firm stand on New York City strongly supporting the full range of reproductive services, sexual health, and gender affirming care; cuts to care in these areas disproportionately impact people with disabilities and would expose people to terrifying outcomes. New York City must stand together to preserve the rights and services that we all deserve.

Finally, there are many other barriers to fully accessible healthcare for New Yorkers with disabilities, and the Council can play a role in changing them: They include:

- **Inaccessible, inflexible and unreliable transportation,** which remains a major barrier for disabled New Yorkers, including getting to and healthcare appointments. The Council must push for:
  - *On-demand and more reliable Access-A-Ride service:* The City of New York now funds 80% of the cost of the MTA's paratransit service, but the City has largely left the administration of the service to NYC Transit. Access-A-Ride riders typically are unable to rely on the city's subways and buses to get around, including to medical appointments. The Council should use its power to demand the MTA significantly increase on-demand service, which allows Access-A-Ride riders to get to where they need to go when they need to, which only about 1,000 of the 170,000 authorized users can do now. The MTA must also improve the reliability of its regular service.
  - *Support full funding of the 2025-2029 MTA capital program,* since a percentage of the total funds included within go towards subway elevators and other accessibility upgrades per our 2022 settlement agreement with the MTA.

Thank you for the opportunity to testify today, and we look forward to working with you on many of these issues.

Asian American Federation

**Testimony for the New York City Council**
**Committee on Mental Health, Disabilities, and Addiction,**
**Jointly with the Committee on Hospitals**
*April 21, 2025*

Written Testimony

Thank you, Chair Lee and the Committee on Mental Health, Disabilities, and Addiction, as well as Chair Narcisse and the Committee on Hospitals, for holding this hearing and giving us the opportunity to testify. I am Andrew Sta. Ana, Interim Co-Executive Director of the Asian American Federation (AAF), where we proudly represent the collective voice of more than 70 member nonprofits serving 1.5 million Asian New Yorkers.

We are here today to discuss the state of healthcare access for people with disabilities. Under the new federal administration's evolving immigration policies, the mental health burden on Asian New Yorkers has exponentially increased, especially those already struggling with a mental health condition. This challenge is exacerbated by immigrants' growing reluctance to engage with formal systems of care, as they are afraid that going to the hospital or clinic will endanger their safety or that of their family by putting their immigration status at risk. Additionally, this challenge compounds the trauma that Asian New Yorkers experienced during and after COVID, during which Asian Americans have experienced the greatest number of anti-Asian assaults in recent history.

As a research and advocacy organization for the pan-Asian American community in New York City, AAF leads the Asian American Mental Health Roundtable, the only coalition of Asian-led, Asian-serving CBOs providing linguistically and culturally competent clinical and non-clinical mental health services and resources. Between 2020 and 2024, AAF's mental health partners have provided over 12,800 Asian New Yorkers with mental health services. To fill critical resource gaps, AAF created the Asian Mental Health Directory of 550 providers and Asian Mental Health Hub, a one-stop of mental health resources in multiple Asian languages.

Since January, our Roundtable members have already witnessed a growing number of community members needing access to mental health support services. Due to the chilling effect of anti-immigrant policies being issued by the new federal administration, there will be an over-reliance on Asian-serving CBOs to provide critical, responsive mental health services. This comes at a time when the majority of Asian-serving CBOs are experiencing significant federal funding cuts that impact their ability to provide social services that support the overall well-being of low-income immigrants.

Therefore, we urge the Committees and City Council members to make the following investments to ensure there is adequate mental healthcare access for one of the city's poorest communities.

Recommendations

1. **Ensure that the unique mental health needs of Asian New Yorkers with disabilities are prioritized when mental health and social service resources are deployed in response to traumatic or violent incidents.**
    - Far too often, individuals with disabilities – particularly those with limited English proficiency – face compounding barriers to accessing timely, culturally competent care. We call on the Department of Health and Mental Hygiene (DOHMH), New York Police Department (NYPD), and all relevant city agencies to provide fully accessible, linguistically appropriate mental health resources that are inclusive of people with disabilities and reflect the diverse cultural and linguistic backgrounds of the Asian community.
    - This includes translating materials into commonly spoken Asian languages and ensuring that translations are not only accurate but also culturally nuanced. Agencies must comply with Local Law 30, which mandates language access for city services, while also ensuring that resources are accessible to individuals with disabilities, which means offering materials in alternative formats such as large print, audio, Braille, and easy-to-read versions, and providing mental health support that accounts for both cultural and accessibility needs.

2. **Linguistically and culturally competent care must be readily available and inclusive of people with disabilities during crisis response and recovery.**
    - The City and its agencies must directly collaborate with Asian-led, Asian-serving CBOs that understand the intersection of disability, culture, and language. AAF's member and partner organizations bring that expertise, collectively providing services in 32 different languages to 18 ethnic groups.
    - DOHMH alone cannot meet this need. Asian-serving CBOs are already doing the work, as they have long-standing, trusted relationships within the community and understand how best to conduct outreach, especially to individuals who face intersecting barriers such as disability and language access. These organizations must be resourced and empowered to lead. However, far too often, they receive referrals from city agencies and systems like DOHMH and NYC Health + Hospitals without the funding needed to actually provide those services. Continued funding is essential to sustaining the exceptional work of these CBOs.

3. **City agencies must support CBOs by engaging in cultural- and disability-sensitivity training, reducing bureaucratic hurdles, offering technical assistance, and allowing organizations the flexibility to tailor services in real time.**
    - These steps are crucial to equipping organizations with the capacity to serve disabled community members in a meaningful and equitable way.
    - We call on the City to invest in preventive, community-based mental health care – particularly for disabled Asian New Yorkers, who are often excluded from both disability and mental health policy conversations. Without strategic investment and an equity-centered approach, the demand placed on these already underfunded, overstretched organizations will only grow, leaving our most vulnerable residents without access to the care they need and deserve.

Thank you for the opportunity to testify on a critical issue impacting the Asian community. We look forward to working together to ensure community members are receiving the mental healthcare they deserve.

**Testimony of Chelsea Rose**
**Policy & Advocacy Manager**
**Care For the Homeless**

**Provided to the New York City Council**
**Committee on Mental Health, Disabilities, and Addiction**
**Committee on Hospitals**
**April 21st, 2025**

My name is Chelsea Rose, and I am the Policy and Advocacy Manager at Care For the Homeless (CFH). I would like to thank the Hospitals Committee Chair, Mercedes Narcisse, the Mental Health, Disabilities, and Addiction Chair, Linda Lee, and the committee members for the opportunity to testify today on the state of health care access for patients with disabilities in New York City. I represent Care For the Homeless, which serves individuals experiencing homelessness, many of whom are living with physical, psychiatric, or cognitive disabilities. We appreciate the Council's ongoing efforts to advance equity and access to health care across the city.

Care For the Homeless has over 40 years of experience providing medical and behavioral health services exclusively to people experiencing homelessness in New York City. We operate 23 federally qualified community health centers in all five boroughs. Our service sites are co-located at facilities operated by other non-profits that include shelters for single adults and families, assessment centers, soup kitchens, and drop-in centers. Additionally, our community-based health center model brings services directly to neighborhoods where the need is most significant. Both models reduce barriers unhoused New Yorkers regularly face in navigating a complex health care system by increasing access to high-quality, patient-centered, primary, and behavioral health services. We also operate two shelters for women and two shelters for men experiencing homelessness, and one Safe Haven all of which have on-site health centers for their residents and the community. In these programs, our goal is to end episodes of homelessness by providing essential supportive services to help our residents obtain stable and permanent housing.

I am here today to talk about the importance of creating accessible health care models that reduce barriers to access for people living with disabilities and to expand our understanding of how disabilities affect individuals experiencing homelessness in NYC.

Accessibility is a core tenet of our model for providing care to individuals experiencing homelessness. Our consumers are burdened with navigating a complex health care system to address multiple co-occurring chronic health conditions. The experience of homelessness exacerbates and often creates

new health conditions that severely impair an individual's ability to navigate the many systems that provide support.

Of the over 12,400 patients Care For the Homeless served last year in our health centers, 40% are living with chronic health conditions that qualify as disabilities under federal law. Despite these conditions being recognized as a disability, the connection between homelessness and health care is often overlooked. At CFH, our focus is bridging this gap to ensure accessible care models are at the forefront of discussions surrounding how to end homelessness.

**Today I would like to highlight three issues affecting the population that we serve. The first is the importance of telemedicine in keeping people connected to primary health care, the second is the barriers to access to supportive services for our aging population in the shelter system, and the third is the need to scale up the services needed to address the needs of people experiencing homelessness and living with severe mental illness.**

**Telemedicine Reimbursement Rates**

Telehealth is a critical access point for providing primary health care, especially behavioral health care services, for many hard-to-reach communities. It has been especially helpful for our consumers living with chronic health conditions that make it difficult for them to travel to one of our sites in person. Our goal is to keep folks connected to ongoing primary services to effectively manage chronic health conditions, especially for older adults that receive our services. In 2024, 28% of our health visits were done using telemedicine and of those virtual visits, half were behavioral health visits.

Despite our patient's reliance on telemedicine services, Medicaid reimburses health centers at just one third of the reimbursement rate for in-person visits. Telehealth payment inequities is one of our primary legislative priorities at the state level, and it would be imperative to have the council's support in enhancing telehealth access by voicing to the state the need to increase reimbursement rates for this critical service. In past years, telehealth payment parity has been left out of the final budget, and it has placed an enormous strain on health centers trying to provide accessible care models for their patients. We, like many health centers across the city, are struggling to continue to offer these services at the current scale.

**An Aging Shelter Population with Complex Needs**

We are seeing an increase in older adults within the shelter system, many of whom are living with serious mental illness or cognitive impairments such as dementia. Unfortunately, shelter providers are not equipped to provide the level of care they require, and we face steep barriers when trying to transition them into a more appropriate setting.

Assisted living facilities and nursing homes routinely refuse to accept individuals with psychiatric diagnoses, particularly those with severe mental illness. Similarly, residents with dementia are often turned away from long-term care facilities that lack the staffing or capacity to meet their needs. While some specialty facilities exist, they are extremely difficult to access.

As a result, too many aging and disabled New Yorkers remain in the shelter system where they receive fragmented, insufficient care and cycle through emergency rooms or hospitals without ever achieving stability. This is neither humane nor cost-effective, and it places enormous strain on staff who are doing their best in a system not designed for this level of medical complexity.

**Long-Term Psychiatric Disability**

Finally, we must address the systemic failure to adequately care for residents with long-term, severe mental health conditions. Many of our clients have cycled in and out of hospitals, shelters, and the streets for 15 to 20 years. Their conditions remain unaddressed due to a lack of coordinated services, supportive housing availability, and long-term psychiatric care options.

Hospitals frequently discharge patients with known histories of homelessness and mental illness without a clear path to housing or continuing treatment. Shelters are left to fill the gap, but they are not equipped to manage complex psychiatric needs. We see residents fall out of care, stop taking medication, deteriorate, and end up back in the hospital or on the street.

The consequences are tragic. People are dying young after decades of cycling through fragmented systems. We need stronger integration between hospitals, behavioral health services, and housing providers. And we need investments in long-term solutions that do not rely on shelters as the default service provider for every need.

As we discuss access to care for New Yorkers with disabilities, we must think holistically. That means funding telehealth at sustainable rates, expanding access to long-term care for aging individuals experiencing homelessness with psychiatric or cognitive conditions, and building real pathways to stability for those with chronic mental illness.

Thank you very much for your time and your commitment to the health and dignity of all New Yorkers.

If you have any questions, please reach out to Chelsea Rose at crose@cfhnyc.org

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**CIDNY Testimony on**

**Health Care Access for Patients with Disabilities**

04/21/2024

My name is Mbacke Thiam. I am the Housing & Health Community Organizer at Center for the Independence of the Disabled, New York (CIDNY). We are a nonprofit organization founded in 1978. We are part of the Independent Living Centers movement, a national network of grassroots and community-based organizations that enhance opportunities for people with disabilities to direct their own lives. CIDNY advocates for people with disabilities in the five boroughs of New York City. We hereby testify on "Evaluating the Current State of Health Care Access for Patients with Disabilities."

Patients with disabilities have the right to equitable access to healthcare. This includes language assistance in the person's native language and the use of disability-specific technology. If needed, patients should ask for: American Sign Language (ASL) interpreting or Communication Access Real-time Translation (CART) services, papers in Braille, large print etc. Also, healthcare workers should receive specific disability training that should educate them on Americans with Disabilities Act (ADA) compliance and specific accessibility and technology requirements.

Patients with mobility issues encounter several barriers to accessing quality healthcare: physical accessibility issues, lack of accessible medical equipment, medical professionals with stigma and bias against people with disabilities, etc. Including a consultant with a mobility disability to advise the operators of healthcare facilities may help reduce its mobility barriers. Insurance coverage can also present numerous challenges for patients with disabilities or chronic diseases. Some insurance coverages charge copays that are high in cost for disabled people. Also, they may fail to cover emergency needs for patients with disabilities. For example, A CIDNY consumer had several issues with his wheelchair and his insurance did not cover the cost of wheelchair maintenance, wheelchair replacement or even repairs. This made it very arduous for him to travel independently.

We know that people with disabilities comprise both people with obvious and invisible disabilities, thus it is important for CIDNY to advocate for those with invisible disabilities. People with mental health disabilities, autism spectrum disorder, traumatic

brain injury, and learning disabilities just to name a few invisible disabilities may need accommodations to receive medical services. For instance, documents may need to be constructed in simple language, the utilization of assistive technology like screen-reading, magnification, and text to speech technology may be necessary for these individuals to complete forms and read information regarding their medical-health needs.

Finally, we recognize that people with disabilities have membership to other minority groups such as race, ethnicity, gender, sexual orientation, age to name a few. Having this level of intersectionality, people with disabilities have higher numbers of mortality attributed to institutional racism. Based on this fact, we must do better to ensure that people with disabilities from all backgrounds can be afforded the opportunity to live and strive in New York City.

We thank the City Council for providing CIDNY with the opportunity to testify. This testimony is supported by Dr. Sharon McLennon Wier, Executive Director of CIDNY. Thank you,

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**Testimony to the City Council on April 21, 2025 on Healthcare access for people with disabilities**

Hello. I am Jean Ryan, president of Disabled In Action of Metropolitan NY and I am a wheelchair user. We have members with all kinds of disabilities.

**People with disabilities have many problems with healthcare access in NYC.**

1. **Attitudes! –** People in the medical profession are not trained to deal with people with disabilities. They ask inappropriate questions. They make assumptions about what we can and cannot do such as asking if we have an aide for a blood draw!
2. **Routine Equipment –** Even in new facilities, the exam tables are way too high. We do not get good medical care just sitting in our wheelchairs.
3. **Communication –** Some places are finally equipped with translation services but they are not good with people with hearing loss or autism or people who are blind or who have low vision. Some staff talk to the aide and not to the patient!
4. **Diagnostic Equipment –** Many changing facilities are not big enough for a wheelchair to fit into a cubicle. Not all tables are adjustable enough for getting onto and if we need help, we are required to bring our own helper, but what if we do not have an aide?
5. **Waiting rooms –** Often there are no cutouts for wheelchair users so we are stuck being in the path of travel or right out in the middle.
6. **Architecture --** High counters we cannot see over, too-high kiosks we cannot use, big monitors covering the low counter if there even is one, and inaccessible bathrooms with low toilets, stalls that do not have room to close behind us, furniture in the bathroom, and bathroom doors that have closers that are too hard to open. This is also true for visitors seeing or accompanying loved ones.

**We did not say anything about awful medical networks, appointments that are months away, and long waits once we are at an appointment.**

**Jean Ryan**
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EPILEPSY FOUNDATION
Metropolitan New York

New York City Council Committee on Mental Health, Disabilities and Addiction
April 21, 2025

On behalf of the many New Yorkers who live with or care about someone impacted by epilepsy, I want to thank Committee Chair Lee, and the Committee members for this opportunity to articulate our commitment to ensuring the continuity of mental health support provision to the community.

The Epilepsy Institute DBA the Epilepsy Foundation of Metropolitan New York (EFMNY) has been at the heart of the NYC epilepsy community for over fifty years. We are New York City's only specialized organization combining epilepsy education, awareness, and advocacy with individualized services such as counseling, psychiatry and vocational supports. Epilepsy is the fourth most common neurological disorder in the world. One in 10 people will have a seizure in their life. Thirty percent of adults living with epilepsy are treatment resistant, they do not achieve control with medication.

Our clients report anxiety, isolation and depression. Depression is the most frequent psychiatric comorbidity in epilepsy. Our patients are often referred by their medical providers, who recognize signs of mental illness. Our therapists utilize a variety of modalities that include trauma informed treatment of depression in both individual and group support sessions as well as self-management workshops. When symptoms of epilepsy or significant side effects from the medications make it difficult to leave the house, the EFMNY pivots to remote services to support our patients to ensure continuity of services. The EFMNY stands ready to support all New Yorkers through providing holistic supports to patients, their families and their communities.

In FY24, EFMNY provided 6,200 therapeutic interventions for NYC residents. For most people this was a weekly service. During a crisis, this may increase to twice weekly. This mental health support is accessible to many of the city's residents *only* because we have the City Council's Discretionary Funding. No one is turned away from EFMNY due their inability to pay for services.

With an enhancement to our City Council Discretionary award, we would hope to achieve the following objectives in 2025:

- Serve more New Yorkers from every borough.
- Increase our attention to overcoming the barriers to accessing mental health support, including addressing the social determinants of health (stigma, employment, culture, access etc.).
- Expand the culturally competent offerings of Group supports to address mental health issues and build community.
- Employ more trauma-based treatment to meet the needs of clients whose mental health is a barrier to their overall well-being.

Thank you for enabling us to meet the mental health needs of New York City's residents.

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EPILEPSY FOUNDATION
END EPILEPSY TOGETHER
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## CITY COUNCIL FUNDING REQUEST– FY2026

**THE EPILEPSY FOUNDATION REQUESTS $300,000 IN FISCAL YEAR 2026.**

The Epilepsy Institute DBA: The Epilepsy Foundation of Metro New York (EFMNY) is requesting $300,000 under the Council's Developmental, Psychological and Behavioral Health Services Initiative. **EFMNY was awarded $259,412 in FY2025.** These funds are critical to sustain the essential services provided to this underserved population; 30 percent of whom are considered medically unstable, resulting in significant economic costs. Our clients living in all 5 boroughs, report significant anxiety, isolation and depression. Many individuals struggle with unemployment, and underemployment compounding low self-esteem.

## Fiscal Year 2026 Enhancement Request

This year, we are requesting an enhancement in our funding to expand our services and continue providing culturally competent, specialty services for people living with or impacted by epilepsy at our clinic. The clinic has a small, multidisciplinary professional staff, providing a range of appropriate therapeutic and support services such as psychiatry, social work, psychology and vocational intervention. Our clinic is the primary service of EFMNY and the centerpiece of the organization's support for New Yorkers impacted by Epilepsy for 50+ years.

At EFMNY, no one is turned away for inability to pay. EFMNY has seen an increase in the number of people seeking services, without a reliable means to pay for supports. Although 40% of the Foundation's NYC clients are covered by Medicaid, the remaining 60% are largely under-insured or uninsured. The eligibility requirements for coverage of service has become more limited. The Council funding supports continuity of care for individuals who could not otherwise access specialized care.

Through this enhancement, we would also hope to increase our attention to the barriers to accessing Mental Health Support, including addressing the social determinants of health (stigma, employment, culture, access etc.) and continue our emphasis on vocational intervention to help clients prepare for and succeed as part of NYC's workforce.

## Organization Overview

EFMNY is New York City's *only* specialized social service agency dedicated to providing those living with epilepsy the critical care they need. For many the psychosocial consequences of epilepsy such as stigma, underemployment, neurological impairment and poverty present equal or greater difficulty than the seizures in everyday life. Those seeking our services not only have seizures but also have co-morbidities including developmental disabilities, mental health challenges and/or access to neurological care. Last year EFMNY's clinical, education and social service programs provided approximately 15,000 services in NYC.

**One in ten people will have a seizure during their lifetime.**

*THANK YOU FOR YOUR SUPPORT*!

New York Lawyers
for the Public Interest, Inc.
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New York, NY 10001-4017
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**Testimony of Nina Shields, Pro Bono Scholar**
**New York Lawyers for the Public Interest, Disability Justice Program**
**To the New York City Council, Committee on Mental Health, Disabilities and Addiction and the Committee on Hospitals**
**Oversight Hearing: Evaluating the Current State of Healthcare Access for Patients with Disabilities**
**April 21, 2025**

Good afternoon. My name is Nina Shields, and I am a Pro Bono Scholar for the Disability Justice program at New York Lawyers for the Public Interest (NYLPI). I want to thank Chairperson Lee, the Committee on Mental Health, Disabilities and Addiction, Chairperson Narcisse, and the Committee on Hospitals for convening an oversight hearing to examine the current state of healthcare access for patients with disabilities. I appreciate the opportunity to provide testimony about the barriers that patients with disabilities in New York City face and the importance of providing accessible healthcare.

## I. Background

Nearly one million New Yorkers – eleven percent of the city's population – have a disability.[1] Anti-discrimination laws, including the Americans with Disabilities Act, require healthcare providers to ensure full and equal access to medical care for people with disabilities by (1) removing physical barriers, (2) providing auxiliary aids and services, and (3) making reasonable changes to policies and procedures.[2]

Despite these legal protections, individuals with all types of disabilities continue to experience impediments to accessing healthcare in New York City.[3] Pervasive inaccessibility exists in hospitals, community clinics, and doctors' offices.[4] The consequences are profound: inaccessible

[1] NYC Mayor's Office for People with Disabilities, Disability statistics in NYC (2021). Available at: https://www.nyc.gov/site/mopd/publications/disability-statistics-in-nyc.page. [IS 2021 REALLY THE MOST RECENT?]
[2] Independence Care System & New York Lawyers for the Public Interest, Breaking down barriers, breaking the silence: Making healthcare accessible for women with disabilities (2012), p. 8. Available at: https://www.nylpi.org/images/FE/chain234siteType8/site203/client/breakingbarriers.pdf ("ICS & NYLPI").
[3] Singer, R.F., I. Dickman, & A. Rosenfeld, Increasing the physical accessibility of healthcare facilities, CMS Office of Minority Health (2017). Available at: https://www.cms.gov/sites/default/files/repo-new/23/Issue-Brief-Increasing-the-Physical-Accessibility-of-Health-Care-Facilities.pdf.
[4] ICS & NYLPI at 1.

healthcare negatively impacts nearly every aspect of an individual's life and leads to significant disparities.[5]

Studies have found that individuals with disabilities are far less likely to access healthcare services than individuals without disabilities.[6] Adults with disabilities are almost twice as likely as other adults to report unmet healthcare needs due to the inaccessibility of medical offices.[7] Many adults with physical disabilities lack access to primary and preventive health services, and only receive episodic care in emergency rooms.[8] Barriers to access often result in incomplete medical exams, lower rates of preventive screenings and recommended treatments, and delayed or forgone care.[9] Women with disabilities, in particular, are significantly less likely to seek or receive quality healthcare in a timely way, especially in the area of cancer screening, leading to delayed diagnoses of breast and cervical cancer.[10] People with intellectual disabilities are also particularly susceptible to unmet healthcare needs.[11]

This significant lack of access leads to poorer health outcomes, including higher mortality rates and shorter life expectancies.[12] For example, although women with disabilities have the same incidence rates of breast cancer as women without disabilities, they are one-third more likely to die from it, likely due to delayed screening and treatment.[13] People with disabilities also experience higher rates of obesity, arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol, and stroke, and people with mobility impairments are at a particularly high risk of secondary conditions such as pressure ulcers, which often go undiagnosed and can

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[5] ICS & NYLPI at 2.
[6] *Id.*
[7] Krahn, G. L., D. K. Walker, & R. Correa-De-Araujo, Persons with disabilities as an unrecognized health disparity population, American Journal of Public Health, 105(S2) (2015). Available at https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2014.302182
[8] Independence Care System, A blueprint for improving access to primary care for adults with physical disabilities (2016), p. 4. Available at: https://icsny.org/wp-content/uploads/2021/11/Independence-Care-System-Blueprint.pdf ("ICS").
[9] Karpman, M., Morriss, S., & Gonzalez, D., Barriers to accessing medical equipment and other health services and supports within households of adults with disabilities, Urban Institute (2024). Available at: https://www.urban.org/research/publication/barriers-accessing-medical-equipment-and-other-health-services-and-supports.
[10] ICS & NYLPI at 2.
[11] Shady, K., Phillips, S. & Newman, S., Barriers and facilitators to healthcare access in adults with intellectual and developmental disorders and communication difficulties: an integrative review, Review Journal of Autism and Developmental Disorders, 11, 39–51 (2024). Available at: https://doi.org/10.1007/s40489-022-00324-8.
[12] ICS & NYLPI at 2. *See also*, VanPuymbrouck, L., Friedman, C., & Feldner, H., Explicit and implicit disability attitudes of healthcare providers, Rehabilitation Psychology, 65(2):101-112 (2020). Available at https://pmc.ncbi.nlm.nih.gov/articles/PMC9534792/.
[13] McCarthy, E.P., Ngo, L.H., Roetzheim, R.G., Chirikos, T.N., Li, D., Drews, R.E., & Iezzoni, L.I., Disparities in breast cancer treatment and survival for women with disabilities, Annals of Internal Medicine, 7;145(9):637-45 (2006). Available at https://doi.org/10.7326/0003-4819-145-9-200611070-00005.

result in repeated hospitalizations and premature death.[14] Finally, research suggests that all-cause mortality rates are higher among adults with disabilities than among those without.[15]

The time for equal, accessible healthcare for people with disabilities in New York City is long overdue.

## II. Common Barriers to Healthcare Access for People with Disabilities

People with disabilities encounter numerous obstacles to comprehensive, quality healthcare in New York City. The most common barriers are categorized as physical, communication, and attitudinal barriers.

- **Physical Barriers**

One of the most prominent challenges for people with physical disabilities is entering and navigating healthcare facilities.[16] Common architectural obstacles include steps; ramps that are flimsy, too steep, or nonexistent; doorways that are too narrow; and restrooms, dressing rooms, and exam rooms that are too small.[17] To ensure equal access, facilities must provide accessible routes from parking or bus stops into a building; accessible parking; accessible entry doors with the required clearance width; clear floor space; maneuvering clearance; accessible restrooms; and accessible signage for people with visual impairments.[18]

Physical obstacles also include inaccessible equipment. Adapted equipment is often unavailable or staff are untrained to use it.[19] Most facilities lack accessible weight scales, transfer lifts, and exam tables.[20] Equal access requires accessible weight scales, exam tables, and diagnostic equipment, including infusion chairs, mammography machines, and radiology equipment.[21]

- **Communication Barriers**

Communication barriers routinely prevent patients with disabilities from fully understanding their medical condition or treatment needs.[22] For example, Deaf and hard of hearing New Yorkers regularly fail to receive a qualified sign language interpreter at doctor appointments and during trips to hospital emergency rooms.[23] This failure to accommodate results in medication errors, missed diagnoses, problems during surgery and anesthesia, missed and delayed appointments, and less complete and accurate information than other patients receive.[24]

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[14] ICS at 4.
[15] *Id.* at 5.
[16] Singer, *et al.*
[17] ICS at 3.
[18] Singer, *et al.*
[19] ICS at 3.
[20] *Id.*
[21] Singer, *et al.*
[22] ICS & NYLPI at 6.
[23] *Id.*
[24] *Id.*

Additionally, people with visual impairments are routinely not provided with important medical information and documents in a format they can read, such as Braille or large print.[25] Finally, with respect to people with developmental disabilities and mental illness, providers often fail to take the necessary time to explain a procedure or treatment option, or to ask what steps are necessary to ensure a comfortable and safe environment for an exam.[26]

- **Attitudinal Barriers**

Attitudinal barriers include provider bias, stigma, lack of training, and lack of disability competency (i.e., skills and attributes essential to providing health care to patients with disabilities), all of which lead to discriminatory treatment. [27] A recent study found that, although most healthcare providers reported not being biased against people with disabilities, when their attitudes were explored implicitly, the overwhelming majority were biased against people with disabilities.[28] Providers' attitudes toward marginalized groups contribute to both healthcare access and health outcome disparities, because they influence behaviors in patient encounters, clinical decision-making, and referral of care.[29]

Providers' lack of disability competency leads to incorrect and detrimental assumptions about people with disabilities.[30] For example, some providers believe that people with disabilities do not have a good quality of life, that people with developmental disabilities do not feel pain and therefore do not require anesthesia, that people who are Deaf have cognitive deficits, and that women with disabilities do not require reproductive counseling and care.[31] These damaging stereotypes, misconceptions, and biases degrade the quality of care patients with disabilities receive.[32] Healthcare providers are also not adequately trained to treat the specific needs of people with disabilities, which leads to preventable inequities in health outcomes. [33]

## III. Efforts to Improve Healthcare Access for Patients with Disabilities

To address these barriers, New York City healthcare facilities must implement changes to their physical structures and equipment, communication methods, and provider training.

Certain facilities are in the process of making such improvements, including New York-Presbyterian Hospital, which, with the help of NYLPI, has begun implementing approximately 1,300 accessibility enhancements, which will lead to life-changing results for the disability

[25] *Id.*
[26] Shady, *et al.*
[27] Karpman, *et al.*
[28] VanPuymbrouck, *et al.*
[29] *Id.*
[30] ICS & NYLPI at 7.
[31] *Id.*
[32] *Id.*
[33] *Id. See also*¸ VanPuymbrouck, *et al.*

community.[34] These enhancements include changes to entrances and loading areas, interior and exterior routes, doors, signage, public restrooms, patient rooms, service counters, nurses' stations, and gift shops; adjustable exam chairs; and enhanced staff training.[35]

These instances of increased accessibility must be replicated citywide as all New Yorkers are entitled to accessible healthcare.

## IV. Recommendations

NYLPI urges the New York City Council to:

- Pass a comprehensive resolution requiring New York City hospitals and medical providers to comply with existing federal, state, and local disability anti-discrimination laws in the ways described above;
- Direct the New York City Health and Hospitals Corporation (HHC) to:
    - Require mandatory reporting from HHC healthcare facilities demonstrating its efforts to comply with existing federal, state, and local disability anti-discrimination laws to ensure that HHC healthcare facilities are accessible for patients with disabilities;
    - Mandate that HHC healthcare facilities procure accessible medical equipment in compliance with anti-discrimination laws and regulations;
    - Require HHC healthcare facilities to notify patients of their right to accommodations and accessible care; and
    - Institute measures to remedy issues related to attitudinal barriers including provider bias, stigma, lack of training, and lack of disability competency;
- Urge the New York State Department of Health to require mandatory reporting from its healthcare facilities demonstrating their efforts to meet their legal obligations to make programs and facilities accessible to patients with disabilities;
- Urge the New York State Legislature to pass legislation requiring that medical facilities procure accessible medical equipment in compliance with anti-discrimination laws and regulations, and require all healthcare facilities to notify patients of their right to accommodations and accessible care;
- Include funding in the budget to assist capital improvements at HHC facilities that are designed to increase accessibility for people with disabilities; and
- Convene annual oversight hearings on the accessibility of medical services and the needs of people with disabilities.

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[34] NewYork-Presbyterian Newsroom, NewYork-Presbyterian, in consultation with disability advocates, undertaking extensive accessibility enhancements benefitting patients with disabilities (2024). Available at: https://www.nyp.org/news/nyp-in-consultation-with-disability-advocates-undertaking-extensive-accessibility-enhancements-benefiting-patients-with-disabilities.
[35] *Id.*

**Finally, NYLPI is grateful for the support our Health Justice program receives from the Council's Immigrant Health Initiative, and we respectfully request that this funding be continued and enhanced in Fiscal Year 2026.**

We look forward to continued partnership with the City Council to advance our shared goals of a more accessible and healthier City for all New Yorkers.

Please feel free to contact me at 212-244-4664 or by email to nshields@nylpi.org and cschuyler@nylpi.org to discuss further.

###

*About New York Lawyers for the Public Interest*

*For nearly 50 years, NYLPI has fought to protect civil rights and achieve lived equality for communities in need. Led by community priorities, we pursue disability, health, immigrant, and environmental justice. NYLPI combines the power of law, organizing, and the private bar to make lasting change where it's needed most.*

*For more information visit: www.nylpi.org*

Kathleen Collins
Telephone No.: [redacted]
Email Address: [redacted]

April 20, 2025

Council Member Linda Lee
Chair
New York City Council Committee On Mental Health, Disabilities and Addiction

Council Member Mercedes Narcisse
Chair
New York City Council Committee On Hospitals

Sent Online at https://council.nyc.gov/testify/
Emailed to: testimony@council.nyc.gov

Re: New York City Council Committee On Mental Health, Disabilities and Addiction Jointly With The New York City Council Committee On Hospitals – T2025-3252 & T2025-3253 - Oversight – Evaluating The Current State Of Health Care Access For Patients With Disabilities

Dear Chair Lee and Chair Narcisse;

My name is Kathleen Collins. I am a native New Yorker who is a congenital quadruple amputee who uses a wheelchair.

I am on the board of Disabled In Action of Metropolitan New York, Inc. (also known as Disabled In Action or DIA). Disabled In Action is a 501(c)(3) grassroots civil

rights organization run by and for people with disabilities. Disabled In Action's mission is to eliminate discrimination for people with all kinds of disabilities.

A person would assume that the health care industry would be ahead of the curve when addressing the needs of people with disabilities to receive health care. Unfortunately, sadly this is not the case. New Yorkers with disabilities encounter physical, financial and attitudinal obstacles when it comes to obtaining health care in the City of New York.

Many health care facilities still do not comply with the United States Access Board's Americans with Disabilities Act Accessibility Guidelines (ADAAG). More often than not, health care facilities entrances are inaccessible, and the offices and waiting rooms do not provide spaces for people using mobility devices to sit. Too often, the restrooms, including the hardware on the doors and the force needed to open doors, are not accessible; amazingly, this is true even in highly respected and well-known hospitals.

Additionally, in many cases, the websites for these medical facilities are not accessible nor screen readable. So too, the devices for signing in at a doctor's office at times, are not accessible to people with low vision, who are blind, or who have manual dexterity disabilities. These New Yorkers then are forced to

experience having their privacy compromised when they have to have someone assist them to complete forms, usually in public waiting rooms where their information is heard by others waiting to be called into an examining room.

Further, people with disabilities who are deaf or have low hearing many times encounter obstacles when trying to communicate with doctors, dentists, their medical staff and technicians at health care facilities and hospitals. So too, more often than not, doctors, dentists, their staff and medical technicians talk to the person that may be accompanying a person with a disability instead of talking directly to the person with a disability.

Health care appliances that a person with a disability can independently use to measure such things as blood pressure, heart rate and whether you have COVID are difficult if not impossible to access independently.

Many times, the medical diagnostic equipment that is necessary to diagnose, and evaluate a person's health as well as treat the person are inaccessible to New Yorkers with disabilities.

Similarly, just like with doctors, many dentist offices are not accessible to people with disabilities and even when the office is accessible many times it is impossible to get proper treatment.

New Yorkers with disabilities experience high stress just traveling to and from a medical appointment. Too often New Yorkers with disabilities miss appointments due to Access-A-Ride not picking them up on time. Further, New Yorkers with disabilities are forced to guess estimate when their medical appointment will be done when scheduling Access-A-Ride, an issue that a person in the E-Hail Pilot Program does not experience, provided they have not previously used all the rides allotted to them for that month.

So too, the number of doctors, dentist and specialists available to people who have Medicaid as their health care insurer is very limited in the City of New York and makes it quite difficult for a person with a disability to get proper, affordable, accessible, and timely medical care. Further, the mass of insurance red tape whether you use government sponsored or private insurance that people with disabilities need to deal with just to obtain the most basic services and equipment is unconscionable and traps many people with disabilities in the best of circumstances, and shockingly maims or kills them in the worst situations.

Finally, there is too much emphasis on institutional care instead of home care for people with disabilities, including, but not limited to, New York's elderly population,  This does not make sense, that is dollar and cents. The COVID pandemic as well as studies have shown that home care is safer, more cost effective and efficient than institutional care as well as complies with the right of people with disabilities to stay within their community. See, ***Olmstead v. L.C.***, 527 U.S. 581

(1999). “Home is where the heart is” and as Dorothy in the Wizard of Oz so aptly stated “There is no place like home”, thus, it is time to change the systemic discrimination against all people with disabilities in New York City, and New York State which is forcing New Yorkers with disabilities into nursing homes and not supporting people with disabilities right to stay safely in their homes.

In sum, there are so many issues faced by all New Yorkers concerning receiving proper, affordable, accessible and timely health care but this is especially critical for New Yorkers with disabilities.

Thank you for this opportunity to speak. I reserve my right to submit additional comments within seventy-two (72) hours after the hearing has been closed.

Sincerely,
Kathleen Collins
Board Member of Disabled In Action
of Metropolitan New York, Inc.

My name is Miranda Stinson DeNovo, and I'm the founder of Long COVID Safety Net, which advocates for people with Long COVID and other infection-associated chronic illnesses such as ME/CFS to get better access to healthcare and social services.

I'm here today to testify about an overlooked issue that affects this growing population and many others, and that's communication access: specifically, how healthcare in New York City continues to be inaccessible for people who are unable to make phone calls, whether because of an auditory disability or a speech disability.

To give some context on how I'm using the terms auditory and speech disabilities:

Auditory disabilities include being Deaf or hard-of-hearing, but can also include auditory processing disorders. In my community of people with Long COVID, a common and perhaps surprisingly disabling symptom is hyperacusis, or extreme sensitivity to sound—which can make holding a telephone call extremely painful if not downright impossible. One person I have worked with has such severe hyperacusis that she would sometimes experience seizure-like episodes and lose her ability to speak—leading the person on the other end of the phone to inevitably hang up.

Speech disabilities, of course, can come in a myriad of shapes and sizes—so in the interest of time, I am going to borrow the broad definition used by the advocacy nonprofit CommunicationFIRST, to encompass anyone who "cannot rely on speech alone to be heard and understood." This can include people with developmental disabilities including autism; brain injury and stroke survivors; people with neuromuscular disorders like cerebral palsy or ALS; and more. In the context of Long COVID, there are at least two common reasons why someone might have difficulty speaking, the first being cognitive symptoms that affect things like word recall and ability to structure a sentence, and the second being extreme fatigue and muscle weakness. Even if a person can muster the energy to speak a few words, at this level of illness it will almost certainly trigger debilitating symptoms after the fact—a phenomenon known in the ME/CFS community as post-exertional malaise.

Just because someone is not able to speak, does not mean they do not have access to language—or that they are not capable of self-directing their own medical care if given the option to do so in writing. Frustratingly—even when it is explicitly requested as an accommodation under the ADA—many medical institutions and social services agencies refuse to communicate with patients via email or text message, incorrectly citing HIPAA.

While appointing a loved one or caregiver as healthcare proxy may be an option for some, this presents undue administrative burden and requires patients to give up a crucial piece of their autonomy—often at significant risk to their safety. In the worst case scenario, this opens the door for caregiver abuse—which is a form of domestic violence

and needs to be treated as such by the city. Even in the best case scenario, where someone does have a trusted person they can appoint as a healthcare proxy, it takes agency away from the consumer and it shouldn't have to be necessary.

In the vast majority of cases, disabled and chronically ill people do not want to have to use a healthcare proxy. They want to be able to speak for themselves. And 9 times out of 10, that means accommodating their requests to communicate with service providers in writing, whether that be email or text message. I want to reiterate that there's absolutely nothing in HIPAA that says providers can't do this. It's just a little extra work to get it set up.

Additionally, providers of healthcare and social services need to be better trained on using TTY systems, as many people report that they get hung up on frequently and therefore can't rely on TTY. Similarly, providers need to be trained on the broader concept of augmentative and alternative communication or AAC, and develop some familiarity with the common types of ACC that patients may use. In the interest of time, I will refer you back to CommunicationFIRST for more information about AAC.

Long COVID may be a somewhat new phenomenon, but these are not new requests. In fact these are things the Deaf and autistic communities have been asking for for decades, and in the spirit of universal design, I want to remind the Committee that if you build systems to accommodate one disability community, you will likely wind up improving the lives of other disability communities as well.

Thank you so much for taking the time to hear my testimony today. I hope next time you will get to hear it directly from the people most impacted, instead of from me as an intermediary.

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# THE CITY OF NEW YORK

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**(PLEASE PRINT)**

**Name:** Elinor LaTouche

**Address:** 40 Exchange Place, Ste 1700 NY 10005

**I represent:** The Epilepsy Institute (Archbelle + 31 clinics)

**Address:** Above

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**Name:** ANDREW SANTA ANA

**Address:** _____

**I represent:** ASIAN AMERICAN FEDERATION

**Address:** _____

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**Name:** Sonyong Lee

**Address:** _____ (KAFSC)

**I represent:** Korean American Family Service Center

**Address:** _____

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**Name:** Julie Iriesen

**Address:** Deputy Commissioner of Administration

**I represent:** NYC DOHMH

**Address:** _____


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**Name:** Manuel Saez

**Address:** Vice president of facilities

**I represent:** NYC Health + Hospitals

**Address:** _____


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**Name:** Ivelisse Mendez-Justiniano

**Address:** Chief Diversity, Equity & Inclusion Officer

**I represent:** NYC Health + Hospitals

**Address:** _____

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**Name:** Emily Sweet

**Address:** General Counsel

**I represent:** Mayor's Office for People wit Disabilities (MOPD)

**Address:** _____


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**Name:** Christina Curry

**Address:** Commissioner

**I represent:** Mayor's Office for People with Disabilities (MOPD)

**Address:** _____


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☐ in favor ☐ in opposition


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**Name:** Emilio Garcia (Interpreter)

**Address:** _____

**I represent:** MOPD

**Address:** _____

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**(PLEASE PRINT)**

**Name:** Nina Shields

**Address:** _____

**I represent:** New York Lawyers for the Public Interest

**Address:** _____

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*Date:* 4/21/25

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**Name:** EVAN YANICEY

**Address:** 25 Elm Pl Brooklyn NY 11201

**I represent:** Brooklyn Center For Independence Disabled

**Address:** _____

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**Name:** Neal Kwatinetz

**Address:** _____

**I represent:** United Ambulette Coalition

**Address:** 5 E Prospect Ave Mt Vernon 10550

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**(PLEASE PRINT)**

**Name:** Chelsea Rose

**Address:** 30 east 33rd St

**I represent:** Care For the Homeless

**Address:** 30 east 33rd St

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**Name:** Christopher Johnson

**Address:** [redacted]

**I represent:** Self

**Address:**

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*Date:* 4/21/2025

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**Name:** Sharon Brown

**Address:** [redacted] Jamaica NY 11436

**I represent:** Rose of Sharon Enterprises

**Address:** [redacted] Bklyn NY 11238

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