September 22, 2021

Dear Governor Hochul:

The Most Integrated Setting Coordinating Council (MISCC) was established in 2002 and is responsible for developing and overseeing the implementation of a comprehensive statewide plan for providing services to individuals of all ages with disabilities in the most integrated setting. As public members appointed to the MISCC, we applaud your commitment to a “new era of transparency" with a focus on “open, ethical governing”.

Although the MISCC was formed nearly 20 years ago in response to a 1999 Supreme Court decision and subsequent NYS Most Integrated Setting Law, New York State has made very limited progress in advancing the right of Disabled New Yorkers to receive services and supports in the most integrated setting.

As a result, the public members identified 4 specific policy objectives affecting all New Yorkers with disabilities: supporting people to leave institutions, enhancing community services and supports, increasing employment rates and conducting a review of the state’s 2013 Olmstead Plan.

While we have made some strides toward downsizing and deinstitutionalizing people from developmental and psychiatric facilities, the most significant failure has been in our state’s nursing facilities where we have both the largest number of institutionalized individuals and made the least amount of progress over these two decades.

It is important to note that one of the most significant barriers to implementing the Olmstead decision is the inordinately low wages paid to home care workers, including consumer-directed personal assistants, who are the alternative to institutionalization in a nursing facility. In upstate New York, these workers make minimum wage and – although they may do complex health-related tasks such as assisting with feeding tubes and ventilators – earn less than the wage our state requires to be paid to fast food workers. The shortage of workers is so dire that Disabled individuals are being needlessly hospitalized due to illnesses arising from the lack of assistance, and some have even sought elective surgeries (such as getting a colostomy or supra pubic drain) solely to address the lack of attendants to assist them with toileting or emptying their bladder.

The deaths of thousands of Disabled and elderly New Yorkers in our state’s nursing facilities and other institutions during the COVID-19 pandemic underscored the need to make significant changes to allow individuals with Long Term Service and Support disabilities to avoid or end unwanted institutionalization. Instead of working with disability advocates to implement specific proposals which would have saved Disabled lives, including those that would have helped ensure equitable access to the COVID-19 vaccine for Disabled New Yorkers, the Cuomo

administration and the New York State Department of Health (NYSDOH) ignored our efforts, refusing even to meet with us.

In part, we attribute the state's failure in addressing these issues to the lack of representation by Disabled New Yorkers in the structure of state government. With no state office representing the interests of Disabled New Yorkers and ensuring accessibility of state operations, our community has been entirely cut out of state government. While we do have multi-billion dollar state agencies that represent the interests of people with developmental and psychiatric disabilities, there is none to represent the needs of people with significant physical disabilities, deaf, blind or the institutionalized Disabled. Consequently, Deaf New Yorkers were forced to sue the Governor to get American Sign Language (ASL) access to his COVID-19 briefings. Even after that lawsuit was resolved, the Governor refused to be filmed with the ASL interpreter and because of the limited scope of the lawsuit Deaf individuals continued to be denied access to vital information about the virus and vaccine. Without even basic access and representation, governance cannot be transparent, open, or ethical.

As community members of the Most Integrated Setting Council, we are recommending the following three things that you can do during your first 45 days as a way to begin to address these issues.

1. **First, extend Executive Order No. 26 (originally established under Governor Mario Cuomo), using the authority under that Executive Order to hire a Chief Disability Officer and establish the Office of the Advocate for Persons with Disabilities.** By signing legislation on your desk (A.3130/S.1836) – passed unanimously by the legislature – you have the power to enshrine the office providing this critical function into state law.

2. **Utilize the enhanced federal FMAP authorized in the American Rescue Plan being used by NYSDOH to increase the wages of home care workers.** These funds were intended to support Disabled individuals in the community and the workers supporting them who are primarily BIPOC. Instead of addressing the wage crisis, NYSDOH ignored the Disability Community and is funneling the funds to managed care companies and nursing facilities. You have the power to correct this injustice.

3. **Require NYSDOH to work with disability rights advocates to implement our proposal – sent to Governor Cuomo on April 2020 – to ensure that Disabled New Yorkers in congregate settings, including nursing facilities, are afforded the opportunity to effectively social distance by leaving those congregate settings for self-quarantine.** https://ilny.us/latest-news/378-disability-advocates-respond-to-governor-cuomo-via-letter-on-covid-19-policies-for-people-with-disabilities-living-in-congregate-settings Although "none of us want a rerun of last year's horrors with COVID-19," only you have the authority to ensure that does not happen. We urge you to use it.

We have begun a process within the Most Integrated Setting Coordinating Council to develop a truly functioning plan through committees which are chaired by public members of the Council who bring years of experience and expertise to bear on issues relating to all New Yorkers disabilities who reside in a broad range of settings and who are all faced with the crisis of attracting and retaining a qualified workforce.

The reception by the state agencies has been mixed. We are writing to request that you meet with us so that we can discuss implementing the above recommendations and update you about our efforts to ensure that the MISCC fulfills its mission.

We agree that "it's time to show the world that 'ever upward' is more than just our state's motto. It's who we are, and it's where we're going." And that applies to all New Yorkers, including those with disabilities. New York's disability community is counting on you to right several of the wrongs imposed on it over the last several decades. While you had no role in causing any of these hardships, you have the unique ability to drastically improve the lives of New Yorkers with disabilities - and in some instances - save their lives. For your convenience, we have provided our contact information below in hopes that we can set up a meeting with both you and your staff in the very near future. Thank you in advance for your consideration of this request.

Sincerely,

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