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Alliance of Long Island Agencies, Inc.

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The Arc New York

Mark van Voorst, Executive Director

August 31, 2020

Governor Andrew M. Cuomo Executive Chamber The Capitol Albany, NY 12224

Dear Governor Cuomo:

On behalf of the not-for-profit providers who deliver the vital supports and services to individuals with intellectual and developmental disabilities (I/DD) across New York State, we wish to bring your attention to the significant failures in leadership that have occurred over this past year, which is currently leading our system towards irreparable harm. Despite decades of honoring New York State's moral and legal responsibility to "[provide] for ... the comprehensively planned provision of services including care, treatment habilitation and rehabilitation of their citizens with developmental disabilities," the COVID-19 pandemic has laid bare the very real and significant deterioration of the service delivery system, of what had once been a strong system. Since the start of the pandemic in March, providers, families and individuals with I/DD found themselves having to fight for guidance, collaboration and resources from the Office for People with Developmental Disabilities ("OPWDD") in order to combat the pandemic. What our community has received in place of leadership and resources, is significant cuts proposed by OPWDD to the service delivery system, which will have profound impacts on people with I/DD's lives and well-being. To fill that void and to correct the trajectory, for what had once been a leading system in disability supports, we respectfully request your immediate intervention to provide the necessary leadership to ensure New York honors its statutory obligations to people with intellectual and developmental disabilities by ensuring that supports and services are available.

From the start of the pandemic, our sector struggled to be recognized as a significant component of the public health system, including our certified residences and providers, who are responsible for keeping our particularly vulnerable population safe and out of hospitals. As such we have struggled significantly with the ability to obtain access to testing, receive the essential worker status our field deserves, and be designated a priority in the distribution of and access to PPE. Furthermore, providers statewide have experienced extensive staffing vacancies and had to develop and implement "combat pay" strategies to ensure coverage in our 24/7 operations and we were forced to privately negotiate and procure PPE with absolutely no financial assistance and very little logistical support from the state.

Providers have also been forced to develop their own contingency plans for quarantine and isolation in residential programs without any state operational or financial support, despite numerous requests for assistance and guidance. These residential programs were left to finance the cost of the emergency on their own, without any financial support from the state to meet the increased costs of responding to the impact of the emergency. As of May 31st, the not-for-profit providers have incurred the following financial impacts directly related to the pandemic:

- Total Additional Payroll Costs \$73.7 million
- Total Additional PPE Expenses \$16.7 million
- Total Other Expenses \$9.5 million
- Total Decrease in Revenue \$74.8 million
- Total Net Financial Impact \$174.7 million
- Providers with less than 30-days of Cash on Hand 41% (25% increase Statewide from December 2019 NYDA Survey)

On May 27th, in the midst of the COVID-19 pandemic and without any discussion or notice to the provider community or to the families they support, the Department of Health ("DOH") announced proposed cuts in reimbursement for IRA and ICF residential programs by eliminating the occupancy adjustment resulting from vacancies and slashing reimbursement by 50% for retainer days when residents are in the hospital or are visiting family. Finally, after cutting reimbursement by 50% for leave days, the proposal also would impose an annual "cap" of 96 therapeutic leave days, after which reimbursement would be reduced to zero. This action would remove over \$230 million from providers already besieged with losses from the pandemic.

In addition to the size of the cut, this proposal has been interpreted to be a backdoor way to reduce the number of certified beds in the state, shrinking the number of opportunities for families to access needed supports. Also, the proposed elimination of the occupancy adjustment resulting from vacancies signifies a substantial departure from longstanding state policy and is not consistent with the current process in which OPWDD fills vacancies in certified residences. The State controls when people's beds can be filled by another person and they also control when and who can go in those spots. Since 1984, OPWDD has recognized that upon the death or relocation of an individual, no provider could fill such vacancy without incurring a reasonable number of vacant days, and thus the funding methodology has included funding for up to a 3% vacancy rate. Additionally, the proposed policy also ignores the State's ongoing support of a requirement imposed by the Willowbrook Community Advisory Board - where an individual's current placement opportunity must be reserved until their return from a hospital or nursing home, regardless of the anticipated length of stay and whether or not it is even anticipated they will return. The circumstance of filling a vacancy is entirely outside the control of the provider and providers do not wish to challenge such decisions due to the historical importance of the settlement agreement to our field and to the individuals who once lived at Willowbrook. Additionally, the rationale offered by OPWDD for these cuts is that if an individual is not physically in his or her residence, there is no reason for the residential provider to be paid in full during such absences since the provider incurs no costs for that individual, which is not the case. 80% of the cost of residential programs is salary paid to direct care staff, clinical staff and residence supervisors. The

absence of a single resident does not in any way reduce the need for a full complement of staff to provide for the needs and ensure the health and safety of the rest of the residents. Consequently, as mentioned previously, the process in which filling a vacancy is controlled by OPWDD and the State often takes months to fill a vacancy. Additionally, the current process is riddled with significant problems, for example, many times providers will be referred an individual for a vacancy and the referral is entirely inappropriate for the vacancy. Before the state eliminates the occupancy adjustment, significant reforms and flexibility is needed to the process, suggesting this cut is premature, at best.

Furthermore, as the providers of supports and services to more than 80% of individuals with intellectual and developmental disabilities in the State, we feel that it is our duty to raise the following significant concerns related to the proposed reduction of reimbursement for retainer days for when residents are in the hospital or when individuals are taking therapeutic leave days for family visits and the imposition of a cap on therapeutic leave.

First, the reduction of reimbursement and imposition of a cap on therapeutic leave is not consistent with the community integration goals fundamental to the HCBS waiver.

The reduction of reimbursement due to extended vacancies that are the result of necessary hospitalizations, sets forth a discriminatory policy for individuals who have serious medical and/or psychiatric disorders and creates a perverse disincentive for the providers who provide supports and services to the most medically frail individuals. Additionally, some individuals have significant mental health issues that may result in the need for extended periods of inpatient psychiatric care due to behavioral issues. It is not unusual for an individual with I/DD to be admitted to a hospital for weeks or months at a time. Furthermore, under OPWDD rules, providers are mandated to keep residential slots open and unfilled throughout the entirety of the hospital stay or other absence from the residence. Therefore, no savings can be derived by the provider agency, but to the contrary, when an individual is admitted to the hospital, staff are typically assigned to provide coverage in the hospital, where residential staff are there to advocate for the individual, interface with the hospital staff and ensure that the individual's needs are met. Thus, hospitalizations result in increased costs to residential programs.

Most recently, in late August, OPWDD informed the provider associations that DOB has chosen to institute a 20% withhold on all non-Medicaid State share payments effective immediately and for an unknown duration of time. This policy will target programs that support families and enable people to stay in their homes, both of which are critical supports during the pandemic. The removal of rental supports and much needed family supports, when our community is struggling to maintain people with significant needs in their homes, is utterly unacceptable. To that end, we will be sending a separate correspondence to address the significant systemic problems that has been created related to this policy and the elimination of the state share payment of day program retainer days.

Therefore, as we previously stated, this pandemic has compounded and exacerbated the significant challenges that our sector has faced due to a rate rationalization system that already had multiple

programs and providers on the brink of insolvency. The leaders of this field are willing and able to work with you and request your leadership to turn the future of this service delivery system around as we face great fiscal uncertainty and significant programmatic changes. Time is short. Further missteps may cause irreversible harm. But we believe that with your leadership, we will be able to develop and implement a plan that embraces the entire private and public sector supports in place for people with disabilities, and strategically realigns, reconstructs, and ultimately improves the system for the people all across New York who depend on it.

We thank you for your consideration of our concerns and request.

Sincerely,

Seth Stein, Esq.

Executive Director & General Counsel

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