

NYC FAIR

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NYC FAIR TESTIMONY BEFORE THE 2021 JOINT LEGISLATIVE BUDGET HEARING ON MENTAL HYGIENE FRIDAY, FEBRUARY, 5, 2021 9:30 AM

Thank you for the opportunity to address this 2021 Joint Legislative Budget Hearing on Mental Hygiene, as a representative for NYC FAIR. My name is Carlene Braithwaite. NYC FAIR is an Advocacy and Resource group of families and concerned individuals advocating on behalf of individuals with Intellectual and Developmental Disabilities (IDD) across the entire spectrum of need.

Permanent Roll Back of Proposed October 1, 2020 Cuts

It is hard to overstate the importance of adequate funding for those vulnerable IDD populations who rely on the supports provided by New York State as a lifeline for their everyday existence especially during this critical time period. Over the past year, the not for profit agencies who serve the IDD community have been hit by the prospect of yet another round of crippling cuts, which if not permanently put on hold, will result in a loss of vital services to those with intellectual and developmental disabilities.

The Office of People with Developmental Disabilities (OPWDD) has proposed cuts in Medicaid Home and Community Based Waiver Programs, which were scheduled to take effect on October 1, 2020. Those proposals were estimated to result in 238 million dollars in cuts to residential programs and if carried through would likely force some providers to close their doors. Those ill-conceived cuts may be delayed until May 1 of this year, but we urge the members to press for a permanent end to these cuts. These cuts target not for profit providers that provide services to those in residential settings. They are based on the false assumption that monies may be saved when individuals served are temporarily away from their residence either due to hospitalizations or for therapeutic leave. Providers, however, must keep these beds open during those absences and costs continue for rent, insurance, utilities and staff. Reimbursement for those costs must continue or providers may be forced to shut down the residences in order to be able to provide other services.

Workforce Crisis

The backbone of day to day support for individuals with developmental and intellectual disabilities rests with DSPs – direct support professionals. DSPs perform the support work. Their responsibilities include: daily hygiene, grooming, feeding, supervision, medication administration, lifting, bathing, transporting, teaching, helping protecting and guiding. While ten years ago the wages paid to DSPs were 35% more than the minimum wage, today wages are just at minimum wage, and in some areas of the State below the minimum wage paid to fast food workers. It is not surprising therefore that turnover rates for DSPs continue to be high, with surveys reporting a 36 percent turnover rate in New York in 2019 with 2/3 of those DSPs voluntarily leaving the sector that year. The pandemic has put even more strain on these individuals who continue to show up to work knowing that they are exposing themselves to infection.

Recruiting and retaining a strong workforce in the nonprofit sector where DSPs are employed is essential to sustain the system of supports for this vulnerable population. Every new hire costs the providers about \$5000 to train – a hidden cost that could be saved by paying these heroes a wage that reflects their dedication, care and responsibilities. With continued pressure placed on the budgets of providers, due to cuts in services as well as unreimbursed expenses sustained during the pandemic, there is little hope that service providers will be able to offer wage increases to the DSP workforce under the current budget. We urge members to focus on this issue and support proposals to pay this workforce a living wage.

Residential Funding Clarification

One of the most critical issues facing the IDD community is the continued failure of the State to move people off the residential waiting lists and the State's failure to provide transparency as to their plans for moving people off those lists. Residential services are expensive. The Budget briefing book indicates that "OPWDD currently supports 36,000 individuals in certified community-based residential programs funded with \$5.2 billion in public resources annually" (Budget Book at 118). Yet it is our understanding that thousands of individuals are now placed on lists, waiting years for residential placements. Many of those individuals are supported in their homes by families with aging parents and caregivers, who understandably are anxiously pressing for placements while they are still able to oversee the process and ensure that their family members receive placements appropriate to their needs.

In the executive budget summary, we are told that OPWDD's plan going forward is to manage access to these services 'based on need'. Residential options are summarized as including access to supports such as "rent-subsidized apartments", "Supportive IRAs", and "Family care" (foster care) (Briefing Book at 119). Another option is "Certified" residences which, as noted above, are allocated through the use of long waiting lists. Certified residences are presently

higher in cost but are so because they are utilized to house those with higher needs, whether medical or behavioral. The State should not be allowed to balance its budget by squeezing a key component of the needed service delivery system – the availability of certified higher need residential opportunities for the IDD community.

The State has expressed the desire in this Budget to move individuals from residential school settings into State operated facilities which are entirely state funded. There is also mention of the move of those in State operated facilities to voluntary provider-based settings. Those in residential school settings, which have aged out of school-based programs, cost the state more as those individuals once they “age out” are fully funded by the State. What is lacking in this proposal is sufficient detail on how individuals will be identified for such complex moves and how individuals and caregiver/parent desires, based on individual needs will be taken into account. We urge members to ask questions about these details before it approves a budget that seems to be based on these assumptions and to ask OPWDD to disclose how any savings from these moves will be deployed.

Of most importance, we urge members to require transparency from the State as to its plan for residential placements and to ask questions to make sure that this Budget addresses those needs. Service access, including access to residential supports, should be person-centered with options offered and tailored to meet the needs of those individuals served. The IDD population’s needs are varied, some do well in supported apartments, others require more structured supports in certified residences. Person centered delivery requires that those on waiting lists living at home who do need certified residential support should not be blocked from certified settings until their older parents and caregivers are no longer able to care for them.

We emphasize that OPWDD should be required to implement a more detailed plan for allocation of residential services, at the same time this budget is approved. This plan is needed in order to ensure that these questions are addressed, the procedures are clarified and that there is transparency so that individuals, families and advocates understand the procedures for residential placement. Families and individuals need to know where they are on the waiting lists, and how those on the waiting lists are prioritized. We note that in 2016 the legislature required that OPWDD report every two years on the number of individuals requiring placement, but that has not occurred. In addition, as a beginning, in order to address in detail the State’s plan for the provision of all services, the members should require OPWDD to develop the comprehensive plan report which it has failed to recently issue and which is required by 5.07 of the Mental Hygiene Law.

Troubling Cuts to Care Coordination Organization (CCO) Payments

The CCOs were established to provide conflict free enhanced care management services with a Care Manager assigned to help individuals with funded supports and services, including health care services. While the roll out of Care Management has not been without its problems, with reports of ineffective care managers, the organizations have provided very good service during the pandemic, supporting and advocating for members and families. We are troubled by reports that in addition to the previously reported cut in reimbursement payments to CCOs from the State, they may face additional double-digit cuts. Families and advocates need to understand the State's proposals, including the impact of cuts on the CCOs' financial wellbeing, well before those funding cuts move forward. As those who now manage the relationships with providers and DDROs on behalf of individuals including development of person-centered Life Plans and their implementation, the CCO is critical to the delivery of services under the current system. Light should be shed on these cuts which could imperil CCO efficiency if not their continued ability to exist. All those affected by such proposed cuts, especially individuals and families supported by CCOs, many of whom rely heavily on CCOs to advocate for them, should have an opportunity to see the State's proposals and provide their input.

Vaccine Priority

Individuals with intellectual and developmental disabilities were hit very hard by COVID with terrible consequences. Our family members, many with co-morbidities, continue to be at great risk, with the COVID case fatality rate for those with IDD reported to be *three times* the rate of the general population. While those with IDD in congregate settings have now been prioritized for the receipt of the COVID vaccine, there have been troubling reports of difficulties in the actual delivery of vaccines to that congregate population. And despite the support expressed by many members to calls from families, service and health care providers to have the 80,000 individuals with IDD who reside outside of congregate care added to the priority list for the vaccine, the State has yet to do so. We understand that vaccine allocations have been insufficient for those currently on priority lists. However, as the State partners with the federal government to ramp up the availability of the vaccine in the coming weeks and months, we urge the members to press for improved access to vaccines for those in congregate settings and for Statewide prioritization of those with IDD who reside outside of congregate settings in the community.

Finally, we urge the legislature to ensure that those who rely on Federal/State funding to serve the IDD population receive their fair share of any COVID relief federal monies received by the State.

Thank you for the opportunity to present this Testimony.

