

**TESTIMONY TO THE 2021 JOINT LEGISLATIVE BUDGET HEARING ON MENTAL HYGIENE-
FEBRUARY 9, 2021 BY RACHELLE KIVANOSKI, PARENT AND MANHATTAN REGIONAL
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I want to thank the committee members for offering this opportunity to participate in this critical discussion on the OPWDD 2021 budget. I am the parent of a 37 y/o man with autism and intellectual disability who has been receiving services from OMRDD and then OPWDD for the last 30 years. I am also the Manhattan regional co-chair of the Care Design NY Individual and Family Advisory Board, where I strive to represent the interests of all of our members who are receiving, or in many cases not receiving, the full range of Home and Community Based Services.

I believe that it is impossible to view this budget proposal outside of the context of the current pandemic. Parents recognize the extraordinary economic challenges the response to COVID-19 has inflicted on our State. But it is equally important for the State to recognize the exceptional toll this terrible disease has inflicted on people with Intellectual and Developmental Disabilities, their families, and those who work so hard to care for them.

It is well known that people with I/DD suffered a disproportionately high rate of COVID infection and deaths. As reported by OPWDD, as of January 20, 2021, there have been 8,166 confirmed COVID-19 positive cases statewide with 564 individuals who have passed. After a lull in the summer, the infection rate and deaths have resumed.

But there are other, less publicized, consequences. Individuals lost their day and employment programs, their Community Habilitation services, and those in certified congregate settings were unable to see their family members for months because of lockdown precautions. One parent reported that her son's spasticity became so severe after not receiving his essential physical therapy at his Dayhab, that he now requires surgery to release his tendons. Many parents report their loved ones' loss of skills. Many individuals have experience increased anxiety and depression requiring additional medication. Others have exhibited escalating behavioral issues due to loss of routine and social isolation putting their caregivers' safety at risk. Those who survived their COVID infections have lingering aftereffects such as severe headaches, fatigue and irritability.

We are also starting to see an uptick in the percentage of COVID infections in people with I/DD not residing in congregate settings. It is urgent that the State include these individuals in Tier 1B for vaccination as recommended by the CDC. It would be tragic to see a further rise in infections and a potential delay in these individuals returning to their programs.

In addition, young people who have aged out of the education system literally have no programs to attend and many have experienced delays in approval for Self Direction services. Waiting lists for certified residential placements continue to grow as placements are delayed.

Direct Service Professionals performed heroic work, risking their own health to care for our loved ones, sometimes without adequate Personal Protective Equipment. They often worked under the duress of quarantine conditions in a residence with individuals who are unable to grasp the concept of social distancing or tolerate masks or perform proper hand hygiene independently. They had to assist individuals with accessing virtual programming and Telehealth appointments. Yet many DSP's still work below minimum wage or only slightly above which has contributed to staff turnover rates hovering around 40% for many providers. We are told that the 2.5% increase in the OPWDD budget is allocated to bring the remaining DSP's who earn below minimum wage up to minimum. But these are not minimum wage jobs. Caring for people with I/DD requires a broad and skill set, compassion, creativity and commitment. These workers more than deserve fair compensation.

For many people with I/DD, particularly those residing in the community who were unable to access their usual support systems, or those who many not have strong family involvement, the Care Coordination Organizations served as their lifelines. Care Managers made sure they had food and medication and provided essential social support. They assisted members to access deferred medical care. They made sure entitlements were secured and did not lapse. They promoted flu vaccination and educated members about the COVID vaccine. And they advocated for service approvals when the DDRO's were slow to respond. For many individuals, their Care Manager was their only point of contact as programs remain closed.

Even once the pandemic is under control and programs can begin to reopen, we are very worried about providers not surviving the prolonged loss in revenue. Will their beloved DayHab programs continue to exist? Will the vocational training sites reopen or welcome our family members back? Will there be enough CommHab staff to assist our loved ones both in provider-based programs and under Self Direction? Will there be sufficient residential opportunities for those who need them?

It will take years for individuals to regain their sense of stability and recover physically and emotionally from the deprivations they have endured. The OPWDD budget needs to consider strengthening services to meet the demands of the recovery period. Instead, we see a budget proposal that appears to consistently underestimate the magnitude of the challenges for this especially vulnerable population.

The I/DD service sector has been systematically defunded for the last 10 years. Providers have received no COLA in that period and there is no COLA in the current budget which left a substantial number of providers with depleted cash reserves. Even

more damaging, the October 1, 2019 HCBS 1915 Waiver implemented cuts to certified residential reimbursement rates that were estimated to result in \$238 million dollars of lost revenue to residential providers. Please note that this plan was developed well before the pandemic before it was released as a “done deal”, impervious to the concerns of the people affected.

During the comment period last spring, many of us pointed out the cruelty and shortsightedness of reducing payment for vacancies, inpatient stays and therapeutic leave days with family, precisely when the second wave of the pandemic was predicted to hit. While we are grateful that providers have been verbally informed that these reimbursement cuts would be deferred until May 1, 2021, they remain like the sword of Damocles, threatening the fiscal viability of many providers who may well have to consolidate or close residences to make ends meet. In fact, we have witnessed the closing and consolidation of a number of OPWDD group homes and an ICF in the last four months, disrupting the lives of individuals and families without warning. As an aside, it is interesting to note that ICF residents, who are the most complex requiring a higher level of care, are excluded from enrollment in a CCO, so OPWDD alone serves as judge and jury for these most vulnerable individuals who may also lack a family advocate to support them.

OPWDD has not conducted a residential needs survey since 2016, although mandated by the Legislature to do so every two years. They have not submitted a strategic plan for residential services or other waiver services as required by 5.07 of the Mental Hygiene Law since 2012-2016. Yet even with this outdated information, it is obvious that there are a growing number of aging family caregivers and aging people with I/DD in addition to a larger than expected numbers of people qualifying for waiver services and entering the OPWDD system. Overall spending is essentially flat and clearly not keeping pace with these growing needs.

This lack of planning and transparency extends to the budget document itself. While we all hope that individuals who are overstaying in residential schools can find a suitable residential opportunity in an OPWDD managed group home, how will this actually be implemented? What happens if the individual or family declines the offered placement as being inappropriate? Will they be forced to return to their parents’ homes whether the parents can manage their care or not? What if the people who are being asked to relocate to a voluntary provider’s home prefer to stay in their current residences? Will they, too, be under pressure to agree? In reading the proposal, I couldn’t help but feel that our loved ones were being viewed as interchangeable widgets that had to be moved around to meet stated financial goals as quickly as possible, without genuine concern for their particular needs.

In translating the projected \$25 million savings into numbers of people, it would appear that approximately 100 residential slots would be set aside for the residential school “over-stayers”. If successful, what guarantee do we have that the \$25 million savings

will remain in the I/DD system and not just transferred to the General Fund as has happened in the past? If savings are realized, they must be allocated to the expansion of services to people with I/DD.

The Budget briefing book states that all new people interested in residential placements will be offered services “based on need”, which is summarized to include access to supports such as subsidized apartments, supportive IRA’s and Family Care, with no mention of Supervised 24 hour IRA’s among the alternatives. Based on statements from OPWDD leadership over the last two years to family stakeholders indicating that group homes are just too expensive, it is impossible for families not to wonder if this option will be now “off the table” for community placements.

Will the 2100 (and growing) applicants currently on the Certified Residential Opportunities (CRO) waiting list be steered toward other lower cost alternatives, whether it is the best or safest option for the individual? Will financial incentives offered to financially strapped providers to move people out of supervised IRA’s result in some unintentional pressure on these families and individuals? Will we be left with only emergency placements for people who need 24 hour supervision, or will they wind up in emergency rooms leading to inappropriate placements in homeless shelters, psychiatric institutions or nursing homes? We all believe in people residing in the least restrictive environment of their choice. But that has to be a true choice, with a full range of services, not primarily driven solely by fiscal goals.

Finally, the Care Coordination Organizations (CCO’s) have been verbally informed of a pending 23% reimbursement cut which comes after a 16% last year, for a 39% cut over two years. It would be unreasonable to expect any organization to provide a high level of care with this magnitude of a cut.

Part of the rationale given was that enrollment in these health homes has exceeded the number originally budgeted for, even though the CCO’s are mandated to accept all applicants. The State is proposing this Draconian cut even without the benefit of cost report data. How is it reasonable that the CCO’s are being so severely penalized for a problem not of their making? This, once again, reflects the general lack of a strategic plan. Given the incredible growth in autism diagnoses alone in the last 20 years, the increased need for HCBS waiver services was entirely predictable.

With the mandate of conflict-free care management, the CCO’s are the sole institutional bodies that advocate solely for the needs, desires and rights of people with I/DD when interfacing with providers and OPWDD. Their mission is to protect the health and safety and quality of life of our loved ones. It is precisely in this period of public health challenges and fiscal instability, that we need desperately need these organizations to support people with I/DD. It is it truly unconscionable to decimate them now.

We have a system in crisis unprepared to meet the current and future needs of our loved ones. What families and individuals want from OPWDD is transparency, choice and true person centered care. We ask our representatives to help us achieve these goals by obtaining a clear and detailed strategic plan from OPWDD for service development and support for this growing and vulnerable sector, particularly in the aftermath of this devastating pandemic. We ask you to stop the cuts to I/DD funding to prepare for the enhanced service needs for pandemic recovery and the full range of residential services. People with I/DD, their families, and the DSP's, providers and CCO's that support them deserve no less.