

**TESTIMONY
SUBMITTED TO
THE NEW YORK STATE ASSEMBLY
STANDING COMMITTEE ON MENTAL HEALTH AND
DEVELOPMENTAL DISABILITIES**

**Hearing on
The Adequacy of Supports and Services for
Individuals with Developmental Disabilities**

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If the focus of OPWDD Transformative Agenda for supporting people with developmental disabilities is to ensure that they “**enjoy meaningful relationships, experience personal health and growth, live in the home of their choice and fully participate in their communities**”, then we must evaluate how best to navigate the obstacles currently preventing us from fully realizing these goals for ALL New Yorkers with developmental disabilities.

In New York City, approximately 2.5% of the 8.5 million residents have a developmental disability and need life long supports including but not limited to: housing, services at home and in the community, and care from direct support professionals. The majority of New Yorkers with developmental disabilities cannot afford the services they require without state assistance.

The 2014-2015 state budget eliminated \$330 million from OPWDD service investment spending over the next three years, thereby lowering the State’s investment in supports and services for people with developmental disabilities. That \$330 million would have supported critical new services for individuals with developmental disabilities, services that would move us toward better supporting people so that they can in fact lead meaningful lives in their own communities.

Direct Support Professionals (DSPs) - the essential caregivers who provide the vital services to the DD population - are earning such abysmally low salaries that they are leaving the field, and new ones are nearly impossible to recruit. These highly trained and compassionate professionals make sure that more than 125,000+ individuals with developmental disabilities receiving state funded supports can lead the most fulfilling lives possible – and yet, the fast food industry pays a higher wage.

Funding from the Medicaid program for DSP salaries is insufficient to pay competitive wages, leaving these professionals in chronic short supply and those positions with high turn over. How can we sustain this incredibly important workforce, when the funding isn’t there to pay competitive rates and encourage growth and loyalty?

When we talk about trying to reach the collective goal of having people live in the home of their choosing in the community, we must also be realistic about the challenges faced by individuals with disabilities on a fixed income living in NYC. Most of these individuals face a crisis when it comes to finding suitable, paying jobs – especially if their support needs are great. The average New Yorker needs to earn \$38 dollars an hour to be able to afford the City median rental of \$2500 a month. Unfortunately, the current state-funding source only provides \$1300 a month for a housing subsidy.

As you might imagine, this does not even begin to take into consideration the rental costs of an accessible apartment. Typically, NYC accessible housing requires an elevator – which doubles the cost of rent. Accessible apartments in NYC simply do not exist for \$1,300 dollars a month.

To make matters more complex, individuals who rely on Medicaid and SSI in order to be eligible for critical services, are boxed into waiting on city subsidized housing lists for an average of ten years, at best.

Let me share with you a few stories – out of hundreds, if not thousands – that illustrate this desperate need:

Mahamodou is completely non-ambulatory teenager who still attends NYC Public School. He lives in a 4-floor walk-up with 4 entranceway steps. His father and home health aide carry him up-and down whenever he leaves the apartment (at least 5 days a week for school). His wheelchair is left in the lobby, with a donated chair when in his house; he is often left lying down on the couch, except when eating. He is severely underweight, and his doctor's want him to gain weight before considering surgery to correct other ailments. There is no elevator and his dad is a small-framed man himself, so Mahamoudou's weight gain would be somewhat bittersweet...He and his family are definitely in need of better more accessible housing.

Vanessa lives with her mother in an apartment building, which has 5-6 steps before entering lobby with elevator. Furthermore, the building is situated in a cul-de-sac hill, and Access-A-Ride matrons want Vanessa's mother or a home attendant to bring Vanessa down the steps and down-the hill to the corner because they often cannot park and get Vanessa from the building. Vanessa was approved for 4hrs housing services but the agency providing the services prohibits the home attendant from lifting her down steps to the van. The family petitioned the landlord to build a ramp over entrance steps nearly 10 years ago, and despite a visit from an elected official, nothing became of it.

This last story I share with you is short but it represents the major issues with NYCHA as it pertains to simple health and safety issues.

Kevin lives in public housing and uses crutches to walk. Several of his floor tiles are missing, creating serious trip hazards in his home. Despite many requests, Kevin has been waiting on NYCHA to fix this for 7 years.

In light of all of this – and with respect to the “transformation” effort – how can we work together to creatively keep people in the community, in safe, affordable housing?

Individuals and families want to be close to the community where they feel they best belong. Many have already found housing they can afford, but as demonstrated by the stories you just heard, these homes are not accessible.

The creative solution we have developed – our Doorways to Independence Program - is to offer cost-effective home modifications and housing case management in the right places, at the right time. Modifications such as ramps, lifts, automatic door openers, accessible bathroom, widening doors, and kitchen adaptations, enable individuals to live independently in their own homes.

With nearly 20 years of expertise delivering these home modifications, we have found that for \$5-25k we can keep someone in affordable housing, in their community, and avoid the high sticker cost of out-of-home placement (like nursing homes, hospitals, and certified residential sites.) We currently have more people on our waiting list for these modifications than our funding will support.

So – If we cannot find a creative solution to raising the NYC monthly residential subsidy from 1,300 to meet average accessible housing costs; we MUST increase the funding for programs like Doorways to Independence, which have proven time and time again to be the solution families and individuals need.

This issue is about more than just a service subsidy or slot. This issue is about making a smart, truly transformative investment in a real, community based future for people with disabilities.

As the state moves toward a managed care model – we must think very carefully about funding and how to have the highest impact possible for the people at the core of the issues we are discussing today.

We feel very strongly that Not One Cent should be pulled from current funding for individuals with developmental disabilities to fund a managed care bureaucracy. We have been told that the funding for managed care infrastructure and administration will come out of “savings and efficiencies.” However, the record shows that it will more likely come from cuts in services and additional rate reductions. With the average cost of a managed care bureaucracy between 8% and 13%, this would mean additional cuts to supports and services of \$400 million or more. Residential, day, clinical and other essential supports cannot sustain those cuts. In fact, if we stay true to our promise to New Yorkers - funding should be expanded to meet the needs of the underserved.

Analysts agree that there are efficiencies and savings to be found in managed health care, but not with managed long term care supports and services for individuals with developmental disabilities. The only savings to be found in employment, day, and residential services is by providing fewer supports and services to fewer individuals. Therefore, under any managed care system, the funding must continue to be used for supports and services and Not One Cent of the funding can be diverted to fund anything else.

I beg each of you – who have come here today to listen to these moving testimonies - to consider all of these issues with caution, concern, and with a great deal of creativity. We simply cannot reach the goals set forth by the transformation agenda without increasing funding for services and supports, sustaining the workforce that provides care to those in need, and making access to affordable, accessible housing a reality. We believe in the goals set, but need your support in creating a real path to achieve them.