

Testimony submitted by Supporting Our Youth & Adults Network in response to the Joint Legislative Budget Hearings-Mental Hygiene 2/5/21
Oral testimony by Leslie Feinberg, Director

To Liz Krueger, Senate Finance Committee Chair
Helene Weinstein, Assembly Ways and Means Committee Chair
Senator John Mannion, Chair of Senate Committee on Developmental Disabilities
Senator Samra Brouk, Chair of the Senate Committee on Mental Health
Assemblyman Tom Abinanti, Chair of Assembly Committee on Developmental Disabilities
Assemblywoman Aileen Gunther, Chair of the Assembly Committee on Mental Health

On behalf of SOYAN I greatly appreciate the opportunity to speak with the Joint Legislative Committee addressing the proposed budget for the agencies that meet the needs of our most vulnerable citizens.

SOYAN is an organization of family members and self-advocates dedicated to preserving dignity and self-determination for people with intellectual and developmental disabilities (I/DD), safeguarding the progress gained for them and protecting and enhancing their quality of life in the community.

We applaud OPWDD's current focus on innovative ways to create more community based options for people with I/DD, based upon the individual's needs, goals and preferences. NYS has long supported people living in the community with individualized supports. The success of Self Direction, as well as model programs providing wrap around supports and services, has demonstrated that people can live quality lives in their communities and at lower costs to NYS than traditional settings. However we cannot forget the devastating impact of the failed deinstitutionalization movement of people with mental illness in the 1980s. Although designed with the premises of supporting these vulnerable citizens in the community, the failure to provide sufficient community based supports lead to the well-documented high costs to individual dignity and NYS. Please do not replicate the possibility of these types of devastating insults to be applied to our most vulnerable citizens with I/DD. The short term benefits of decreasing funding for vulnerable people is outweighed by the many long term costs to the state.

Many of the thousands of people with I/DD currently living with their families don't have the needed supports and services necessary to live independently. There are limited supported opportunities available. If funding was increased, then people would have better quality lives. The current situation has aging caregivers caring for aging individuals. This is a disaster in the making.

Our fear is that OPWDD's current proposal will limit 24/7 opportunities and force families to keep their loved ones at home...but without a long term plan. As primary caregivers age, this becomes more problematic. We have trouble finding OPWDD current 5 year plan that would hopefully provide insight into the nuts and bolts of how OPWDD's mission will be accomplished. This gives us cause for concern that these proposals are more aspirational than practical.

OPWDD funding pays a wage to the many real people who support real people with I/DD living in the community. OPWDD states there are 126,000 people living in their communities who are receiving the agency's support. These paid essential workers are supporting their families in their communities thereby supporting the NYS economy: they

buy groceries, go to restaurants, pay income taxes, pay rent and mortgages. We ask you to remember to include a living wage to our essential workers.

We are pleased to know that NYS continues to evaluate the feasibility of a managed care service and support delivery system. We still have concerns and have yet to uncover any state that has successfully created a managed care delivery system to provide for the long term needs of people with I/DD without jeopardizing health, safety, and quality of life.

We again support the state's efforts to increase employment opportunities for adults with I/DD. The prospect of increasing our loved ones ability to earn a wage opens the door for them to become fully participating in the growth of NYS economy. We look forward to increased opportunities for person-centered job development, job placement and job coaching and of course, ongoing long term employment. In our society, an adult feels empowered when they receive a paycheck for a job well-done, and, to share the dignity of having a job in the community.

The proposed budget designates \$15M towards increased housing development. This is a great start yet not sufficient. We wonder about the data OPWDD is collecting to make decisions about present and future housing needs. We look forward to subsequent budgets continuing the development of truly integrated housing options for people with I/DD.

We are pleased that OPW currently supports 6700 individuals with rental subsidies allowing people with I/DD to live self-directed lives in their communities. In many counties of the state, this rental subsidy is insufficient to allow people to live in their communities where they have developed community connections and have natural supports. These rental subsidies have not been increased in over 5 years. This must be reevaluated to enable people with very limited incomes to live in their communities. SOYAN has been working on a no-cost-to-the-state housing initiative and would welcome the opportunity to discuss it in greater detail with members of this committee.

We are relieved that the 20% withhold against state-funded non-Medicaid local assistance payments has been modified to a 5% cut. To be clear people using Self-Direction and living independently in the community cannot absorb a 5% cut to these non-Medicaid reimbursements. These reimbursements are used to pay for critical safety supports, such as utilities and access critical safety services obtained by using their phones and internet connections, such as tele-health

NYS has some of the best supports and programs...across the country. We understand the gravity the pandemic has on current budget issues, but these issues should not be at the cost of the most vulnerable citizens. Let us not waste the opportunities provided by this crisis to ignore the human cost (people with I/DD have some of the highest mortality rates) of the needs of NYS citizens with I/DD.

Thank you for providing families with the opportunity to share the thoughts that run through our minds and keep us awake at night. We need OPWDD's mission to be actualized: we help people with I/DD live richer lives.