



Self-Advocacy Association of New York State 2025 NYS Budget Comments and position paper

Many of New York’s citizens with developmental disabilities rely on services through NYS agencies, particularly OPWDD and DOH. These services are essential to meeting our most basic needs, realizing our potential, and maximizing our contributions to our community, state, and country.

It is important that decision-makers recognize that while our supports and services are an essential part of our life, just “getting services” is not enough. Often the services we receive do not afford us the opportunities we seek. Our services should support us to live the lives we wish, to be respected, to be supported in a dignified way, and to realize our own unique potential. They should support us to not just participate in our communities, but also to be valued members of those communities.

There is no “one size fits all” for us. Some of us need support with our most basic needs, such as self-care and communicating with others. We need support which keeps us free from harm and we need to be treated with respect. Also, many of us choose to live and work in our communities and rely on supports and services to do so. Too often we experience a shortage of staffing and find that our most basic needs are not met. We also find significant barriers within our communities which prevent us from living our best life.

It is essential that our supports and services are strong, and there is still much work to do there. In addition, it is time that NYS recognizes that we need to reimagine community. We still face significant barriers to healthcare, gaining and maintaining employment, finding accessible homes and ultimately finding acceptance and belonging. Too often, we find that we are quite limited in where and when we can work, where we can live, and where we can go. We still find ourselves to be misunderstood and disrespected. We still show up to civic meetings, healthcare appointments, activities and events and find that

we cannot be accommodated. We struggle with the limited availability and poor quality of accessible transportation. For these reasons, and more, many of us still feel like we are living lives apart from our fellow New Yorkers.

We want these thoughts to be foremost in decision-makers' minds when thinking about investments in our communities. As decisions are made, please question whether NYS is creating a place for everyone, both in this budget year and those which follow.

There is much in Governor Hochul's proposed budget to be happy about, such as investments in OPWDD's overall budget (particularly those targeting wage increases for Direct Support and other staff), regional disability clinics, affordable and accessible housing, transportation, etc.

We ask that that our legislators stand with Governor Hochul on the areas of her proposed budget which will help improve our lives. However, in some cases we ask that those recommendations be improved upon. Most importantly, we ask decision-makers to develop relationships with their constituents who have developmental and other disabilities, to hear from us and better understand our needs, challenges, and wants.

Over the years it has become clear that despite investments and sincere efforts to improve our supports and services, we continue to see the same issues go unsolved year after year. We need to see investments which lead to real solutions for us.

We ask that you look closely at the following areas:

***Support Staff/Workforce Crisis:** New Yorkers with disabilities rely on a variety of staffing support services. Some of us require the more intensive support of certified/traditional services, while others use self-directed and other services to live in our own homes and apartments. Some of us rely on more than one type of staffing support to meet our needs, yet we continue to find that, regardless of the type of staff support we use, wages simply continue to be too low. As a result, we still see high turnover rates and staffing shortages which interfere in all areas of our lives, limit our opportunities, cause us needless suffering, and create real risk to our physical and emotional health.

OPWDD funded Direct Support Professionals: For those of us who make our homes through traditional certified services, we rely on the support of Direct Support Professionals (DSPs). Despite significant investments in wages in recent years, including the current one, we continue to see high turnover rates and live in homes where there simply are not enough staff to meet our needs. We commend the past and current

proposed investments, particularly the continuation of the \$850 million rate increase to voluntary providers. While we are pleased to see that Governor Hochul has also recommended a 2.1% inflationary adjustment, we must ask if this is enough. We are well into our second decade of this staffing crisis. We know that our colleagues in the voluntary provider community and many in the family advocacy community are asking for a 7.8% adjustment, and we ask that decision-makers look closely at the actual need and make investments that will finally solve our staffing crisis.

DOH funded CDPA and HHA Staffing: For many of us living in our own apartments and homes, we rely on CDPA and HHA staff to help us meet our basic care needs. Again, many of us see high turnover and it is not uncommon that we experience a shortage of staff over extended periods of time during which our needs are not met. Like the salaries of DSPs, the salaries for these positions have been too low for too long and we need to see greater investment.

Of significant concern is the NYS transition to a single FI for CDPA services. While we commend efforts to improve the system, we are concerned that a single large entity may be less responsive than smaller local providers. We are gravely concerned that the current plan to transition all 280,000 New Yorkers who use the service, as well as all existing staff, over to a single FI within a period of a few months will cause interruptions or loss of services. If this transition is to move forward, we ask that that NYS does so with caution, developing clear and realistic timelines to ensure that service interruptions and loss of services do not occur.

We also believe that when NYS moves forward with improvements to the CDPA FI system, it must include more robust training to CDPA staff members in disability culture and how to provide supports in a person-centered way. Many of us have found staff members to be unfamiliar with our culture, our values and our needs. The same can be said of HHA staff.

OPWDD funded Self-Directed Community Habilitation Staff: For many of us who choose self-directed services and reside in our own apartments and homes, we rely on community habilitation staff to support us in living and participating in our communities. However, we also experience high rates of staff turnover and staffing shortages. We commend OPWDD for engaging in an assessment process to determine how to improve our services over time, and we are hopeful that the legislature will invest in those improvements when the time comes.

***Changes to the Nurse Practice Act:** Another concern of ours is the failure of NYS to pass into law the changes to the Nurse Practice Act which have been proposed over the past several years. These changes would allow community habilitation staff to administer medications within the non-certified homes of people using self-directed services. They would also allow individual and/or family members to approve support people to administer medications. SANYS supports changes to the Nurse Practice Act which would make it easier for support staff in community settings to give us the medications we need. We should not be forced into a more restrictive home just because we need help with our medications.

***Transportation:** We applaud the Governor's proposed investments in transportation, and today we ask each of our legislators to go further and look into the communities of your constituents to better understand the widespread shortage of public and accessible transportation across New York State. We need help to arrive at future solutions to this long-standing problem which limits opportunity for so many New Yorkers.

We also ask for support of Assembly Bill: 2025A574 which would increase the number of accessible buses required of transit authorities and expand the service range of accessible buses by 3 miles. This would provide more accessible transportation to more New Yorkers with disabilities who are currently living or working, or seeking to live or work, beyond current service areas.

***Durable Medical Equipment:** Far too many of us experience significant delays when we need new equipment or repairs to durable medical equipment, such as wheelchairs and other mobility devices. When this occurs, it is not merely an inconvenience, but can leave us unable to travel, work, and attend to our most basic needs and wants. It can also lead to harm when delays force us to continue using equipment that no longer works safely, no longer fits our bodies or otherwise fails to meet our needs.

In the Governor's state of the state briefing book, it was stated that:

“Governor Hochul will increase wheelchair access for Medicaid members by increasing rates for clinical specialty evaluation for new wheelchairs, expanding coverage for repairs of previously owned power chairs, and expanding coverage of routine and preventative maintenance for wheelchairs, which will help prevent costly breakdowns, minimize downtime for users, and extend the lifespan of the equipment.”

It is not clear that this is represented in the proposed budget, but it is essential that this promise is kept. We can no longer go without the equipment we so desperately need.

***Housing:** We are thankful for the ongoing investments in affordable and supportive housing and welcome the additional \$15 million specifically aimed at “independent living opportunities for people with IDD” within the OPWDD budget. However, it is important to note that most of the existing and new housing stock in NYS is not accessible. We ask NYS to look aggressively at significantly increasing accessible housing development so that we may be able to choose where we live and work as freely as our fellow New Yorkers who do not have the same accessibility needs.

***Marriage and Benefits:** For too long, many of us have been afraid to marry the person we love due to the risk of losing or having serious reductions of the benefits upon which we rely. We are happy to see current NYS Senate and Assembly bills S1758 and A2242 which seek to protect our benefits by requiring that our eligibility, should we become married, would be determined based on our eligibility status before marriage.

About SANYS

SANYS is an organization founded by people with developmental disabilities, for people with developmental disabilities. We have been “Speaking Up for Ourselves and Others” for over 30 years.

The above statements represent views of the Board of Directors and members of SANYS. For more information, or to schedule a meeting or visit, please contact: Arnold Ackerley, Administrative Director at aackerley@sanys.org or (518) 382-1454 ext. 1600.