



Self-Advocacy Association of New York State
2026 Position Paper
“It’s Time for Real Change”

As New York’s citizens with developmental disabilities, we rely on services through NYS agencies, particularly the Office for People with Developmental Disabilities (OPWDD) and the Department of Health (DOH). These services are essential to meeting our most basic needs, realizing our potential, and maximizing our contributions to our community, our state, and our country.

It is important for decision-makers to recognize that while our supports and services are an essential part of our life, just “getting services” is not enough. We need those services to be more person-centered, providing us with the opportunity to choose the direction of our own lives, rather than having to fit ourselves into pre-determined options that we do not want. There is no “one size fits all” for us. Our services should support us to live lives of dignity and choice, and to have a real chance to fulfill our own unique potential. They should help us to become valued members of our communities, not just passive service recipients.

Toward that end, it is important that NYS invests in us throughout all phases of our lives. Not only do we need increased investments to transform adult services, but we also need New York State to ensure that high quality Early Intervention (EI) services are available for every child who needs them. This is not only the right thing to do; it is the responsible thing to do. EI services have been proven to foster better life outcomes for children with disabilities. Continued and increased investments in EI will also save NY State from spending on unnecessary services once they become adults. NYS is currently failing a generation of children due to a history of insufficient funding for EI services, and this must end.

It is now time for NYS to reimagine the true meaning of community. People with developmental disabilities 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, and we continue to be misunderstood and disrespected. We 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 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. We appreciate the investments in OPWDD's overall budget, particularly the targeted inflationary increases which help voluntary providers keep up with costs and raise DSP and other staff wages. We're also happy to see proposed investments in regional disability clinics, affordable and accessible housing, and transportation.

We ask that that our legislators stand with Governor Hochul on these areas of her proposed budget which will help improve our lives. We also ask you to take a step further by improving upon those recommendations. Your guiding question should not be "What does it take to keep services and supports available?", but rather, "What does it take to create services and supports which promote lives of dignity and real choice?".

While we cannot lay out for you here a complete plan of a new person-centered system, we think the most important place to start is recognizing that NYS has been making investments to keep the system running without investing enough funds to actually transform and improve it. This is not to say that there are not meaningful ongoing efforts. We believe, for the most part, that our state agencies are acting in good faith. However, for most of us, our lives remain largely unchanged. It is as if we keep investing to keep a ship from sinking but never invest enough to get that ship to go somewhere new.

Let's start those important conversations today. Ask yourselves what real transformation looks like, what it costs and what steps we can take to get there. Most importantly, we ask decision-makers to develop relationships with your constituents who have developmental and other disabilities, listen to us, and better understand our needs, challenges, and wants.

Please see the following specific budget and legislative priorities for the 2026/2027 budget year.

***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, which are funded by separate NYS offices such as DOH and OPWDD. 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 and attend daily programs 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. We live in homes and attend programs where there simply are not enough staff to meet our needs. Even before the staffing crisis began for most of us, there was not enough staff per shift for us to receive the individualized attention necessary for free choice as to what we do with our days.

We commend the past and current proposed investments and are pleased to see that Governor Hochul has also recommended a 1.7% inflationary adjustment. However, this is not 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 2.7% adjustment. This 2.7% is a minimum requirement, and NYS should go beyond the minimum.

It is time to make significant investments which will not only allow us to retain DSPs but will also initiate forward movement towards a system that can employ enough staff to support us in living lives of our choosing. Investments should not just keep our system running enough to maintain our health and safety but should also yield room for innovation and real change. We must look at what our real staffing needs will be in a person-centered system that allows free choice for people with developmental disabilities.

- 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, yet the released final report does not specify clear recommendations to help solve these staffing challenges. We recognize that there are no easy answers, but we ask that sustained attention and creativity be brought to these issues, and that stakeholders become further engaged in exploring solutions.
- DOH funded Consumer Directed Personal Assistance (CDPA) Program and Home Health Aide (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 even our most basic needs are not met. Similar to the salaries

of DSPs, the salaries for these positions have been too low for too long and we need to see greater investment.

Furthermore, last year's transition to a single Fiscal Intermediary for CDPA services caused significant disruption in many of our lives, and many of us are still facing challenges getting the new system to work for us. The advocacy community had anticipated these concerns and spoke up about them, but it seems those concerns were unheard. This must not happen again, and NYS must do better now with these essential services.

***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 staff 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 with disabilities.

We also ask for support of **Senate Bill A00574** which would increase the number of accessible buses required of transit authorities and also expand the service range of paratransit buses up to 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:** We were deeply disappointed to see that bills **S1616 and A2520** which would have increased rates to Durable Medical Equipment (DME) providers to 100% of the Medicaid schedule were vetoed last year. Far too many of us experience significant delays when we need new equipment or repairs to DME 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. We need you to champion legislation once again this year to increase those rates and we ask that Governor Hochul sign onto that legislation should it pass.

***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 for people who use wheelchairs and walkers or other adaptive equipment. 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.

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 40 years.

The above statements represent views of the Board of Directors and members of the 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.