



Self-Advocacy Association of New York State Mental Hygiene Joint Budget Hearing Testimony

February 4, 2026

As New York's citizens with developmental disabilities, we 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, our state, and our country. Therefore, it is importantly that you develop relationships with your constituents with Developmental and other Disabilities and hear from them regularly to better understand their needs, challenges and wants. We are a diverse group and we at SANYS feel it is important for you to recognize that no one person or organization can speak for all of us.

There is much in Governor Hochul 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), affordable and accessible housing, transportation etc. and we ask that you stand with her on the many areas of her on these important areas which will help improve our lives. However, we ask that you increase the Governor's 1.7% targeted inflationary increase to at least 2.7%. You will hear more on this later

As we prepared our testimony today we recognized that much of what we say here, year after year, is the same because we simply see that, despite investments, policy

changes and other efforts, some of our most fundamental issues go unsolved year after year.

While we are grateful for our current services and supports, for the hard work of those working in our state agencies like OPWDD and DOH as well as those working in our provider, organizations and CCO's, we want to focus today on the need for fundamental systems transformation. We will not focus on specific 2027 budget or legislative priorities here today but we will be sharing a summary document of our specific budget and legislative priorities with you and look forward to speaking more on those as well as our long-term goal of real systems transformation.

We feel it is time that we at all levels of our services system, from individuals served, to staff and provider organizations, family advocates, NYS agencies and you the legislature, admit to ourselves and on another that our system of supports and services has not delivered on its promise to become truly person-centered. It is service-centered rather than person-centered. It is important to say that we do not believe this is the fault of staff members, provider agency administrators or the commissioners of NYS agencies. It is the result of a failure to recognize the basic fact that we need real change and then make sufficient investments over time which will allow for real transformation. It is time that we admit that while real change may be costly, nothing could be more necessary.

For years, we have invested in staff wages, which is so important. Yet we fail to recognize that even before the staffing crisis for most of us there simply were not enough staff on a shift to be able to give us the individualized attention we need to be able to really choose what we do with our days. We need to do more than just solve the staffing crisis we need to look at what our real staffing needs will be in a person-centered system.

We continue to invest in new housing opportunities, again something of great importance. Yet still we find that we are often waiting for years for new opportunities. For those of us in certified residential settings we live with the fact that new opportunities of our choosing may simply never be there for us.

Our para-transit system is still woefully under-funded which prevents many of us from pursuing social and/or employment opportunities in our communities.

People with disabilities deserve consistency, choice, and dignity, not just eligibility, not just services. The system needs to be redesigned so that we can have truly person centered and individualized services. Systems should be designed with disabled people, based on our values, our needs and aspirations.

While we cannot lay out for you here a complete plan of this new system, we think the most important place to start is to recognize that NYS has been making investments to keep the system running without investing enough to really transform it. This is not to say that there are not meaningful ongoing efforts. We believe that, 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.

We never feel like we can thrive as we have to fight to get our basic needs met. We see much in policy that supports person-centered lives, however day to day, in our real lives our system cannot make those policies real. On the most basic level there just are not enough staff do so, and it feels that our provider agencies are struggling to maintain the status quo and lack the ability to really innovate, even when they have the desire to do so.

One simple place to start is to recognize that we don't just need funding to pay DSP's more, we need enough funding to employ more DSP's. So we thank the Governor for her proposed 1.7% targeted inflationary increase, but say that it is not enough. Our colleagues in the advocacy community are asking for 2.7% increase. We say you should provide that increase and more. We should start having meaningful conversations about what it will cost NYS to create meaningful innovation; we should start talking about standards for staffing minimums based upon person-centered needs rather than basic safety requirements. We need staffing patterns that will afford DSP's the opportunity to perform their responsibilities in a person-centered manner each day. It's not just what we deserve, it is also what they, the DSP's deserve.

We don't just need investments in new housing; we need enough housing so we can really choose where we live. People and families should not have to wait years for a first, or a new housing opportunity.

We don't just need higher rates so provider organizations can absorb increased costs, we need enough investment so that provider organizations can innovate and develop programs and practices that are more person-centered.

If NYS truly wants to support a person-centered system of supports and services, we need to be engaging stakeholders in key decisions before they are made. Last year's transition to a single FI for CDPA services caused significant disruption in many of our lives and many of us are still facing challenges to get the support we need to make this work. The advocacy community had anticipated these concerns, but it seems those concerns were unheard. This should not happen again.

We consider today's testimony the start of an important conversation and look forward to speaking further with all of you as well as our colleagues at state agencies, provider agencies and within the advocacy community

We thank you for your time.

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.