



## **Self-Advocacy Association of New York State 2022 Position Paper**

Many of New York's citizens with developmental disabilities rely on services through NYS offices, 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.

For at least a decade, there has been a trend in which investment into the system has not kept up with needs. Consequently, we now see a number of signs that our system of supports and services is at risk. Among these signs is an ongoing staffing crisis, a lack of responsive services, and underemployment among New Yorkers with developmental disabilities.

Considering this, we are happy to say that there is much in Governor Hochul's proposed budget to be happy about. It is clear to see that New Yorkers with Disabilities are once again a priority, and we ask that you stand with our Governor on the many areas of her proposed budget that will help improve our lives.

While it is imperative that decision makers understand this dire need for systems funding, it is also important to consider the many areas of life in which New York's citizens with intellectual and developmental disabilities participate and contribute to the life of their communities, while also making decisions. We have also included such priority areas below.

### **Housing**

Just like many other citizens in NYS, people with developmental disabilities are often held back from achieving their dreams and maximizing their independence and contributions to their community because of the prohibitive cost of housing. People with disabilities' success depends on housing being affordable for all, not just for some.

We applaud the Executive Budget's funding for the \$20 Billion Affordable and Supportive Housing Plan.

Yet, for at least a decade, there has been a trend in which investment in the system has not kept up with the need for housing and residential supports.

While NYS continues to invest heavily in traditional services and certified group homes that are needed by some, people with disabilities want others to know about the importance of more independent and innovative services and housing opportunities.

The increase in investments for independent living opportunities for people with I/DD and continued investment in housing subsidy enhancements in the Executive Budget is deeply appreciated. We also strongly encourage a reexamination of housing subsidies for people with developmental disabilities that takes into account market costs, including local and regional costs. Current subsidy rates put up barriers for many to transition to less-costly housing in their communities.

**TALKING POINT:** Investment in programs that support housing opportunities are important because people with disabilities benefit from housing that is affordable and supports their independence.

### **Choosing Where We Live:**

While we commend OPWDD for placing particular emphasis this year on assisting people to enter the least restrictive settings, as well as creating rate flexibility to better support people with significant support needs, we are concerned about the preservation of “Choice”.

While many may benefit from transitioning to in-state opportunities from out-of-state, as well as transitioning from more-restrictive state-operated residential settings to less restrictive settings in more community based settings, we would emphasize that any process for transition must be person-centered, respectful of connections to existing communities, and prioritizing choice in decisions people make themselves or with the support of others who know them best.

In addition, we would like a focus on promoting options for people living in voluntary, provider-operated, residential settings to transition to less-restrictive settings of their choice as well.

**TALKING POINT:** People with disabilities want to live in the least restrictive setting in communities of their choice, and they want to be at the center of processes for making those decisions. The increase in ISS subsidy rate is an important step in this direction but we are asking for more.

### **Employment**

The public health crisis has been devastating for employment of people with developmental disabilities. As we transition to a time when employment options are safer for all, we appreciate the Executive Budget’s focus on employment for people with disabilities.

The increased investments in the 55-b/-c programs to employ people with disabilities in

the state workforce, and the creation of a Chief Disability Officer position, are deeply appreciated.

People with developmental disabilities have long faced a lack of emphasis for funding of employment services since before the economic devastation of the global pandemic. The mass loss of employment in this time has put people years behind in their struggle to find and maintain employment in their communities. We strongly encourage continued support for innovative and diverse options for people with developmental disabilities seeking to start or return to work.

**TALKING POINTS:** We want meaningful employment and options that we choose ourselves.

### **Daytime Activities and Supports**

As with many citizens of New York State, a significant and ongoing worry for New York's citizens with developmental disabilities has been a lack of options and choices for meaningful days that has been exacerbated by our current public health crisis.

We do want to acknowledge the positive impact of the flexibility OPWDD has achieved through remote service delivery options during the pandemic. Yet, we would like to see this flexibility maintained even as in-person programs have re-opened. Many who have benefited from remote service delivery should be able to choose to continue to do so, and our service system should incentivize a wide array of options.

Day programs, similar to group homes, may be appropriate for some but are not felt to be the best option for most. People with disabilities have benefited from support for community-based employment, such as volunteering, continuing and post-secondary education, community and day habilitation, benefits education and advisement that incentivize work, self-directed employment options, supports for job development, and promotion of initiatives that create jobs for people with developmental disabilities, including tax incentives and affirmative action projects have also been vital supports in this area.

We would ask for robust support for the full breadth of service delivery options, rather than a continued focus on congregate programs.

**TALKING POINTS:** We want to be able to choose how we spend our days and how we receive our services.

### **Internet communications technology**

People with disabilities must also be supported to have internet access in their homes as a fundamental right, as well as be supported to use internet communications technology. Currently in our service system, internet technology and the supports to use it remain far from widely available. We have heard from many who have faced isolation and other negative outcomes throughout this crisis due to either a lack of Internet and

devices, or an inability to use communications technology. As some have returned to in-person day programs, they have struggled with finding support to continue to use internet communications in a group setting. We believe that support for the use of Internet communications technology should be a basic requirement for all services.

**TALKING POINTS:** [We want access to the Internet and supports to use it](#)

**Self Determination, Self-Directed Services and CDPA Personal Care Aide Wages:**

For people receiving self-directed services there is a great desire for self-direction to retain its flexibility and freedom as use of this program expands in New York State. Self-advocates using self-direction have achieved significant cost savings for the state compared to traditional services such as group-homes or day programs, which has opened opportunities in more intensive programs for people who truly need and want them. It is important that there be increased investments in self-directed services to ensure that it can continue to accommodate new people and remain sustainable for those currently serviced.

During the pandemic SANYS became aware of a significant crisis for many New Yorkers who are self-directing their services through a combination of OPWDD and DOH services. Mirroring the crisis in DSP workforce is a workforce crisis in CDPA Personal Care Aids.

Just like the DSP staffing crisis that was created through low wages in OPWDD, there is an ongoing staffing crisis in the DOH Consumer Directed Personal Assistance Program.

Many self-advocates who are living in their communities rely on either a combination of Community Habilitation Staff through OPWDD's Self-Direction programming and Personal Care Aids through DOH's CDPA program, or they may rely entirely on CDPA.

CDPA Personal Care Aid wages have been too low for too long. As a result, few potential employees want to work as Personal Care Aids. We struggle to hire these workers who should be there to meet our most basic care needs. Furthermore, unlike people in certified settings who have the safety net of provider organizations, or state employees who can ensure that staff are available day to day, many of us who rely on CDPA staff find ourselves many hours or even days without CDPA staff to meet our most basic care needs. Consequently, many of us are suffering needlessly and some of us have even fallen into hospitals and nursing homes when our most basic needs could not be met.

We also worry that upcoming restrictions on eligibility for personal care and CDPA, including the minimum activities of daily living requirements and the "high needs clinical review," will continue to tear apart a vital system of community-based services and supports.

Sadly, for many of us, when we look at our future, we see fear. Fear of falling out of the life we have built and into services that would remove us from our communities, or worst of all, no services at all. This situation cannot stand any longer. It has taken too many years for NYS to respond to the DSP staffing crisis and we still have a long way to go there. We must not repeat history, we need investments to increase CDPA Personal Care Aide wages. This is essential to our needs. Like all other New Yorkers, we have a right to live in our communities, a right to have lives of dignity and maximal independence. People are really suffering, and it is your duty to act. Therefore, we ask that you add increases in CDPA PCA wages into the new budget and repeal any eligibility restrictions for CDPA.

**TALKING POINT:** We want to preserve the philosophy and intent of self-determination and maintain strong funding and easy eligibility. CDPA and personal care wages must be strengthened.

### **Direct Support Professionals**

Our system was in a staffing crisis before the current pandemic. Now, the pandemic has driven this crisis to a near breaking point, with Direct Support Professionals doing heroic work in the face of dire risks to their health and lives.

We have been overjoyed to see the Executive Budget prioritizing strategies to address the staffing crisis. We ask that you approve the Governor's proposed investments in the following workforce strategies:

- healthcare worker retention bonuses that would help incentivize DSPs to remain in their current positions.
- a much-needed Cost of Living Adjustment.
- pathways to facilitate new skilled workers entering the DSP workforce such as the SUNY For All partnership, Direct Professional Career and Technical Education Program, and the Connect Immigrant New Yorkers to Direct Support Professionals program.

It is important to note that while these investments are essential, they are not enough. We still need further investment to bring those wages up to competitive rates.

Direct Support Professionals must be compensated competitively and fairly for the critical work they do. They must be acknowledged for their sacrifices and heroism during this crisis. New York State must find ways to continue support for the compensation of Direct Support Professionals or risk our system of services and supports breaking.

**TALKING POINT:** Direct Support Professionals must be compensated competitively and fairly. They must be well trained professionals who understand our needs, respect us and help us live the life that we want to live.

## **Transportation**

We are thankful to see investments in transportation infrastructure included in the Executive Budget.

However, to ensure adequate transportation services, people with disabilities want to be included in all of the planning stages, both by active invitation and by events being held in locations that are accessible via paratransit or other means available to people with disabilities.

Transportation continues to be a significant area of advocacy for New Yorkers with disabilities. Paratransit is still not available for many people within their communities, or availability is limited. People in rural areas suffer greatly from a lack of public transportation options. People with disabilities want to feel like transportation is being taken seriously.

People with disabilities benefit when accessible and affordable transportation is a central consideration of all development and community planning. Too often, people are finding their access to employment and the community-at-large limited.

**TALKING POINT:** We believe a lack of transportation options increases costs and problems with all other systems.

## **Managed Care**

At SANYS we remain concerned that no one has yet convinced us that Managed Care will work for Long Term Supports and Services in NYS. We are deeply concerned that managed care would take money from services; in fact, we know it already has, as there are ongoing investments in preparedness while the state waits to make a final decision.

We are also concerned about the lack of a clear plan for how self-direction would work under managed care, and overall, the lack of answers about transition to date has already left many people confused.

Our system needs to become more person-centered, less restrictive, and more community based to survive. It is not clear that Managed Care is the solution, so we need to know New York state's plans, and what the alternative will be.

**TALKING POINT:** We do not support Managed Care going forward as no one has convinced us it will work

## **Chief Disability Officer and Ombudsperson**

We value the creation of a Chief Disability Officer position for New York state, both because of the potential to support the increase of employment of people with I/DD as well as the opportunity to have an advocate for disability issues close to the Governor. Our hope is that the staffing for this office will include people with I/DD, as these voices are critical to have close to a formal disability advocate position.

While the CDO position is clearly important it is also important to our membership that an office of an Ombudsperson for people with disabilities be created. There is a clear need for a statewide position with the independence and power to resolve conflicts for people with disabilities in their systems of services and supports.

**TALKING POINT:** [We support the CDO position, but would also like an Ombudsperson](#)

## **Guardianship & Supported Decision Making**

We believe it is too easy to impose guardianship on a person who doesn't need it in New York State, and it is currently too difficult to restore rights to people under inappropriate guardianships.

Self-Advocates have had positive experiences with Supported Decision-Making programs which have already been piloted in parts of New York State and would welcome a New York State certification for Supported Decision Making Plans

**TALKING POINT:** [Help us maintain our rights through Supported Decision Making](#)

## **We invite you to meet your constituents in their communities:**

We, the Self-Advocacy Association of New York State, ask that you consider today's meeting as the beginning of a dialogue with self-advocates for the upcoming year. Our organization supports self-advocates across New York State and wants to facilitate visits to programs and communities where the voices of people with developmental disabilities can be heard directly. Please reach out to us to help support some of these critical opportunities for engagement with citizens in your districts.

Self-Advocates are excited about overcoming barriers they may face to participating in the democratic process and voting, and SANYS will spend 2022 engaging with our members and partners to promote these activities. Contact with their elected representatives goes a long way to supporting people with disabilities in participating in government.

**TALKING POINTS:** [Visit us in our communities.](#)

## **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 the 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](mailto:aackerley@sanys.org) or 518-603-6706.

Feel free to contact your regional coordinator for more information. A Directory of our regional offices can be found at [SANYS.org](http://SANYS.org).