



Self-Advocacy Association of New York State 2021 Position Paper

For many of New York's citizens with developmental disabilities OPWDD services are essential to realizing successful life outcomes including essential needs such as quality personal care all the way through realizing hopes and dreams such as obtaining independent housing, employment and other meaningful roles within their communities.

For at least a decade, there has been a trend in which investment in the system has not kept up with needs. As a consequence, we now see a number of signs that our system of supports and services are at risk. Among these signs is an ongoing staffing crisis, and a lack of responsive services. We have many people waiting for new residential, and other opportunities, as well as people currently in services facing significant barriers to real choice when seeking new opportunities.

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 that the additional 2% that NYS invests annually simply isn't enough to provide a sustainable system of services and supports which embrace person-centered values and practices.

Our understanding is that the current increase in demand for services exceeds this 2% annual budget growth. Demand may be as high as an additional 10% annually. We ask that NYS recognize that this failure to invest proportionately to demand is weakening the service system.

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, which afford New York's citizens with intellectual and developmental disabilities participate and contribute to the life of their community, while making decisions. We have 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 OPWDD housing development, as well as resources 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 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.

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, but they want to be at the center of processes for making those decisions

Employment

The public health crisis has been devastating for employment of people with developmental disabilities. As we eventually transition to a time when employment options are safer for all, we would call attention to the great need to focus resources on employment for people with disabilities.

People with developmental disabilities faced a lack of emphasis for funding of employment services before the economic devastation of the global pandemic. The mass loss of employment in this time will put people years behind in their struggle to find and maintain employment in their communities. There must be strong fiscal 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. We hope that this flexibility will be maintained even after our current crisis for those who choose to receive services and supports this way.

While some have succeeded with remote service and support options, others have struggled with the format or even the ability to get online. As with all services and supports we would like to emphasize "Choice" and encourage OPWDD to support a robust array of options for people to receive daytime services, and especially to support people's ability to have contact with the communities of their choice.

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, 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.

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 is far from widely available. We have heard from many who have faced isolation and other negative outcomes throughout this crisis from either a lack of Internet and devices, or an inability to use communications technology. We believe that support for the use of Internet communications technology should be a basic requirement of residential services.

TALKING POINTS: We want access to the Internet and supports to use it

Self Determination and Self-Directed Services

For people receiving self-directed services there is a great desire that self-direction retains 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 and have opened up opportunities in more intensive programs for people who truly need and want them.

We are concerned that changes and cuts to options previously available in these programs may impact the success of these programs. Insufficient funding that hinders support for robust self-directed services worry people with disabilities who may risk being forced into more costly institutional services or rolling back gains people have made in being part of their communities. People with disabilities worry about threats to their right to be in the “most integrated setting” if self-directed services were to fail.

We also know that the ability of people to receive services and supports in their own community instead of more expensive institutional settings depends on a strong Consumer Directed Personal Assistance Program. We join with others to encourage a repeal of restrictions on eligibility for personal care and CDPA, including the minimum activities of daily living requirements and the “high needs clinical review”.

Lastly, while we applaud the budget’s intention to turn a 20% withhold on non-Medicaid spending into a 5% personal cut, it does not make sense to us that any cut whatsoever would exist on this type of spending during a global pandemic. We encourage a complete restoration of funding to non-Medicaid spending.

TALKING POINT: We want to preserve the philosophy and intent of self-determination and maintain strong funding and easy eligibility.

Direct Support Professionals

Our system was in a staffing crisis before the current pandemic, with service providers struggling to keep employees in essential jobs with insufficient investment from the State.

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.

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 robustly support 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

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.

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.

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 have growing worries that managed care would take money from services, we are 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 in order to survive. It is not clear that Managed Care is the solution, so we need to know what alternative will be.

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

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 2020 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 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.