



2024 Self-Advocacy Association of New York State (SANYS) Policy Statement with Talking Points

Direct Support Professionals (DSP) Pay

The staff supports we depend on to live are in crisis because DSPs are not getting paid enough. If New York State does not give more money for DSP pay, we will be at a higher risk for harm. Until this problem is fixed, NYS is going backwards not forward. Over the long term, the cost of our unmet needs will lead to higher costs for NYS as more people will require hospital stays or to live in less independent and more costly settings.

We support the governor's campaigns and other investments to raise awareness about the need for workers and to help make hiring easier.

We want:

- ◆ A 3.2% Cost of Living Adjustment (COLA) to pay DSPs more
- ◆ A \$4,000 wage enhancement to be paid to DSPs

Talking Points:

- People with I/DD in New York State are already being hurt by programs closing, good staff leaving their jobs, and unfilled staff positions.
- When people cannot get the care they need, they suffer in physical and emotional ways and this needs to stop now.
- When people cannot get the care they need in the community, they may be forced to move back into hospitals, nursing homes, or other institutional settings that cost the state more money.
- The Governor has proposed a 1.5% increase in the COLA, but we believe this is not enough to help people. We need a 3.2% increase this year and the \$4,000 wage enhancement to keep the staff that we depend on.



Consumer Directed Personal Assistance (CDPA) Eligibility

#RestoreHomeCare

Recently passed changes to how people get CDPA (self-directed home care) will make it harder for us to live in the community. If no action is taken, these changes will take effect before March 2025.

We want:

- ◆ Restore Home Care by undoing the recent changes to how people get CDPA which make it harder for us to get this service.

- ◆ Pass bills S328/A6346

Talking Points:

- CDPA stands for Consumer Directed Personal Assistance, and it is a program of self-directed home care through the Department of Health that helps people live in the community.
- Many people with I/DD depend on CDPA to stay out of institutional settings like nursing homes.
- The new changes to how people get CDPA will make it harder for many, many people with I/DD to get these services. Right now, a person only needs support in one Activity of Daily Life to qualify for CDPA, but the new changes will require support in at least two areas. They will also restrict the program to people who need physical supports rather than people who need non-physical supports like verbal cueing or hand-over-hand prompting. This change will shut out many people with I/DD who need non-physical supports to live their lives.
- Passing bills S328 and A6346 would repeal these changes and allow people with I/DD to continue being supported in the community.



Nurse Practice Act

SANYS supports changes to the Nurse Practice Act to 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.

We want:

- ◆ Pass bill A7740 to allow more of us living in the community to have staff help us manage our medication.

Talking Points:

- Right now, some people with I/DD can't live in community settings because they depend on staff support for taking medication, which can only be supervised by a nurse in a certified setting.
- Passing bill A7740 would allow nurses to decide if a person or their family can train staff to give medications in community settings. This would help people avoid health risks and continue to live in their own home or apartment. It would also make it possible for many more people to live in the community.



CDPA Pay

We want to live in the community instead of expensive institutions, but low pay for CDPA staff is making it difficult to do so. This year's budget cancels some CDPA pay increases from past years.

We want:

- ◆ Higher pay for staff in the CDPA program so that people can keep living in the community
- ◆ Pass the Fair Pay for Home Care bill A6329/S5374A to make sure home care staff get paid above the minimum wage

Talking Points:

- The Governor's budget wants to cut "wage parity" money that would have raised pay for CDPA staff.
- Many people living in their own homes are struggling to have their basic needs met. Many suffer discomfort, pain, and the indignity of not having their personal needs met in a timely way on a regular basis. They often choose to suffer through this rather than return to institutional settings or to a home that is not their own.
- This money would make a big difference for people trying to get staff support in the community. Taking it away makes it more difficult for people to avoid institutional settings like nursing homes.
- We also support the Fair Pay for Home Care bill which would help home care staff in New York make at least 150% of the minimum wage.
- Setting wages at 150% of the minimum wage would encourage staff to continue working in this field and would save money for New York State by keeping people out of expensive institutional settings.



Managed Care

SANYS has said for a long time that we would only support Managed Care for people with developmental disabilities if 2 conditions are met:

1. We want to know that Managed Care would make our services better.
2. We want to know that Managed Care would not take away money from services that already exist.

So far, NY State hasn't shown us that Managed Care can do either of these things.

If approved, we want to better understand how Managed Care would affect us, and we want to be included in the planning process.

Talking Points:

- From the information we have seen, there is no evidence that Managed Care for people with I/DD would improve the quality of services, and there is no evidence that Managed Care would not take money away from services.
- We understand that a transition to Managed Care for I/DD services has not yet been decided, but right now we are speaking up against this move.
- People with I/DD had many complaints about the stakeholder process run by Guidehouse earlier this year about a possible transition to Managed Care. People did not feel heard in this process and felt that it was run by an organization that does not know people with I/DD very well. It is important that Guidehouse get to know and really understand people with I/DD and their families.



Olmstead Plan and Employment First

We thank the Governor for investing \$250,000 to create an Olmstead Plan for New York, which would help people living in institutions better understand their rights and their choices. We look forward to working with the Most Integrated Settings Council as they create and share the plan.

We also thank the Governor for trying to make New York an “Employment First” State with a \$6.7 million investment. This means that people with disabilities will be offered, and supported to be part of, job programs as a top priority.

Talking Points:

- An Olmstead Plan for New York would help many people with I/DD who want to know their rights and options around institutional care and living in the community.
- It’s important to us that we participate in the creation of an Olmstead Plan directly, so our voices are heard.
- Many people with I/DD in New York want a system of residential services and supports that makes “choice” a top priority. There are many people who currently live in more restrictive settings than they need or want, and they need a clear and quick process for transitioning to more appropriate and less restrictive settings.
- We believe every person with I/DD who is offered services through OPWDD has a right to explore employment supports first before other services are offered.
- Investing in Employment First will significantly help the ability of people with I/DD to be part of their communities.



Durable Medical Equipment

Organizations that provide Durable Medical Equipment (DME) must be successful so that we can get the equipment we need to live our lives. We are worried that smaller businesses which provide DME will go out of business because of higher costs and lower payments they get from Managed Care.

We want:

- ◆ Pass Bill S3468/A3408 to make payments fair and to support smaller providers that we know and trust to stay in business.

Talking Points:

- People with I/DD who depend on Durable Medical Equipment benefit the most from providers who know them well and have known them for a long time.
- The “race to the bottom” that has been caused by Managed Care organizations offering lower rates for DME services has hurt the providers that we value the most.
- We believe that higher rates for DME will lead to better and more available services, even in rural areas. This will save New York money over time by increasing the ability of people who depend on DME to live in the community.



Housing and Transportation

We are at increased risk when we cannot afford available places to live and when accessible public transportation is not reliable. It is harder to live in the community and have a job without affordable housing and reliable transportation.

We want:

- ◆ More money for affordable, accessible housing in places we want to live
- ◆ More money for accessible transportation, especially in rural areas
- ◆ Inclusion in planning for accessible and affordable housing and transportation
- ◆ Improved transportation services so that all parts of our communities are accessible

Talking Points:

- While we know that most transportation planning in New York is done on a regional level, we support efforts by the state to clarify the rights of people with disabilities in transportation planning.
- Paratransit services allow people to be a part of their community, to work and volunteer, and to have relationships with others. Cuts or limits on paratransit services lead to the segregation of people with disabilities and risk forcing people into institutional settings.
- Investments in transportation in New York State benefit people with disabilities by helping our communities become more connected.
- People with disabilities also depend on affordable housing that is accessible and located in places where people want to live.
- Without affordable housing, many of the community-based services and supports for people with I/DD do not work.