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Self-Advocacy Association of New York State, Inc. 2014 Legislative and Policy Platform

Reimagining our Future

The theme for our annual conference this past year was, ***Reimagining our Future***. We thought a lot about this theme before choosing it. When we looked up the word reimagine in the dictionary, we found that it means to reinterpret imaginatively, to rethink. We know these are hard things to do in the middle of budget challenges and pressure from the Federal Government, but that is what we need to do.

We believe we need a new vision for how we, and others with developmental and intellectual disabilities are supported. The vision that our organization has is one we have been talking about for many years.

OPWDD's current system must be transformed to a true ***people first system***, one that provides person-centered supports to all including the many people who need 24-hour support. Individual supports do not mean everyone lives by themselves, or spends all their days by themselves, it means that people have a choice of who they live with, where they live, how they spend their days and who supports them.

Individualized support includes employment, opportunities for community service, adult education, supports for inclusive recreation and other community activities that allow for participation and integration into the daily life of our communities.

All of the above is necessary, not only to develop a sustainable array of supports for all people who need services, but also to comply with the US Supreme Court's Olmstead Decision and directives from the Center for Medicare and Medicaid Supports (CMS).

Individualized supports and choices also include opportunities for self-determination and self-direction. Many of us, including those who depend on the support of our families, want to hire our own staff and control our own budget, even when we receive supports from agencies.

We believe much of the Governor's budget is a good step forward in this direction. We support the Governor and OPWDD's plan to transform services.

We agree and disagree with CMS

We agree with what the Center for Medicare and Medicaid Services (CMS) says about the need to transform the supports provided by the Office of People with Developmental disabilities (OPWDD). There are over 18,000 people supported by OPWDD living in places with more than 8 people. There are more than forty thousand people spending their days in settings that are not integrated. That is what CMS is talking about and why CMS created a new Rule about home and community based services that assures people's rights to privacy and choice of settings.

Where we disagree with CMS is what seems to be a belief that this change can happen in a short time. We are talking about people's lives here, our lives; making choices from among options, developing person centered plans, ensuring safety, getting people connected in their communities. System transformation has to be about people, and it has to be a thoughtful process. It is easy to reimagine a funding stream; it takes time to help people and their families reimagine where they might live or how they want spend their day and time also to create those opportunities.

As we evolve and transform the current system of supports for people with developmental disabilities, it is helpful for us to have a clear understanding about how the system is organized and how money is spent. We understand that out of every dollar that OPWDD currently spends to support people with a developmental disability to live in their community, 91 cents supports people to live in residential facilities and only 9 cents to live in their own home or apartment. For employment, 91 cents of every dollar is spent to support people to participate in day services, and only 9% is spent to support people to work. In New York, we get what we pay for.

Support for OPWDD's Transformation Plan

Transformation is about people and it is about spending money in a people first way that evolves that system thoughtfully. We support OPWDD's transformation plan. However, we hope that CMS will recognize some progress in the next few years and acknowledge the challenge of quickly transforming a large system that has been developed over many years. OPWDD needs to stay focused on change but needs the time to support people to transform or reimagine their supports in a way that is meaningful to them and their families, with a large array of choices in the communities where they want to live.

Funds for people in need of and waiting for services

As we transform the way we currently spend money, we must insure that there are enough funds for people who are waiting for services. Our system saves money when people move from high cost services to lower cost services, and we must reinvest all those dollars in services for people who are in need. We also have to make sure that funds are available for students with disabilities coming out of school to transition to employment and/or to do things that they find interesting in their communities.

Direct Support Professionals

We need well-trained, well-paid and caring staff to support us in our homes and our communities. Many of our staff have not had a pay increase in a number of years. Many of our direct support staff members work two jobs just to get by. We urge the Governor and the legislators to find a way to provide a cost of living adjustment for our dedicated staff. We need them!

Finally, when we are talking about the system, we are talking about those of us who receive or are waiting for supports; we are talking about families who need support also. We believe we **are** the system.

The following pages include specific statements we have written about:

1. Development Center Closure: SANYS supports the closure of developmental centers. Everyone has the right to live in their community with the supports they need. This has been our belief since the founding of our organization in 1986.

2. Employment and other supports: We need to reimagine how our system supports us to work, contribute to our community as volunteers (community service is a pathway to employment for many), continue our education and job training, and pursue hobbies and other interests. It is these activities that help us get and stay connected to other members of our communities.

3. Current legislative bills and issues that we feel support a people first agenda: There are some important bills and issues to consider in the 2014 legislative session.

1. SANYS supports the closure of Developmental Centers

Since the beginning of our organization in 1986, SANYS has advocated for the closure of all institutions. From that point of view, the closure of the remaining Developmental Centers has been a long time coming. People with developmental disabilities, even those with challenging histories, belong in their communities with the supports they need to be full and contributing citizens.

A People First View of Developmental Center Closures

SANYS agrees with the Center for Medicare and Medicaid Services (CMS) directives and with OPWDD's transformation plan. Closure should begin with each person presently living at the development center, and the use of a person centered planning process that focuses on the needs of that person and their goals for their life, including their wishes about where to live, who to live with, and in what community. We understand that many people will have to live with others to afford the staff supports that they may need. However, the size of a home should not be based on a fixed amount of people. It should be based on the needs of people and their choices, including who to share a small home or apartment with. SANYS believes that smaller homes are a better alternative for people who will move from developmental centers and that adults should have the privacy of their own bedrooms.

We know that many of the people currently living at developmental centers have some unique needs for support and we believe that OPWDD should consider the most individualized supports possible, even when people are living in a group home.

Development of Community Resources:

Currently, OPWDD's developmental centers do provide a resource to people, their families, and communities. The closure of the developmental centers will mean that OPWDD will need to develop local community resources for people with unique challenges, including those living at home with their family.

SANYS believes that people with disabilities, including those who need extraordinary supports, have a right to live in the community of their choice, with the support they need to be contributing citizens.

We fully support OPWDD's plan to develop the New York Systemic Therapeutic Assessment, Respite and Treatment (NY START) program, a new initiative to address the need for available community-based crisis prevention and intervention services to individuals with intellectual and developmental disabilities and co-occurring behavioral health needs.

Rejection of some of the public comments that we have heard:

There have been some public statements that OPWDD is closing the Developmental Centers for purely financial reasons. We reject that claim. Closing developmental centers is the right thing to do for the people who live in these facilities, but it is also part of an important transformation of OPWDD's current system of support to a more individualized, community-based system. It is a shift in thinking, and it is a shift to a People First way of spending money and resources.

New York State has one of the most facility-based systems of support for people with developmental disabilities in the country. For example, as stated previously, in addition to those in developmental centers, over 18,000 New York citizens with developmental disabilities live in places with more than eight people. Now our state must comply with the recent requirements for transformation expectations of CMS, which include the closure of developmental centers and dramatic increases in community living options such as individualized and self-directed supports and small group settings with more choice and control by the people who live there. There must also be an increase of integrated work and other meaningful activities in the community.

SANYS's board recognizes that the closure of an institution can be disruptive to all including employees, families, and the community. We hope that closure can occur in a way that no one currently employed loses opportunities for continued employment. We also hope that communities that are financially impacted by the closure receive the support they need from government to repurpose and reuse the space made available when an institution closes.

Finally, we understand there are tensions around the decision to close a facility, but we urge people not to make negative statements and generalizations about people currently living at Developmental Centers, who will be moving into communities. Members of our organization want to remind everyone that the people who are living in the developmental centers are sons and daughters and brothers and sisters and former members of the community. They are citizens and they have rights, including the right to live in the community with the supports they need.

We'll end our statement on closing developmental Centers with the following quote.

"People with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights." – **Governor Andrew M. Cuomo**

2. Employment and other things we want to do with our days

We need to reimagine how our system supports us to work, contribute to our community as volunteers, go to school, pursue a hobby, retire, and basically do things that we are interested in and that help us to connect to others in our communities. We have a lot to offer.

For many of us, choice in our system is limited. More than 30,000 people with developmental disabilities attend day habilitation programs most days, 8,000 thousand people work at workshops. 9,700 people receive supportive employment services, but only 5,600 people are actually supported to work at a job in their community, and most of these jobs are part time, some very part time. This means that most people spend their days in segregated settings.

We need to create a whole new way of supporting people over the coming years. We need opportunities to work, to contribute and to be part of our communities. And change is coming to our system to support these ideas.

NY's Olmstead plan requires that people have opportunities to live and work in the most integrated setting, meaning in the community not a facility. One of CMS's expectations of OPWDD is that workshops be phased out in the coming years. Related to this, the National Council on Disabilities is seeking an end to the 14 c exemption that allows organizations to pay a subminimum wage. Many self-advocates are upset about this change because workshops provide some income and have been an important alternative to day habilitation programs.

The SANYS' Board will continue to support self-advocates and others to talk about these issues together and speak up for the kinds of support they want as OPWDD transforms the supports people can receive for employment and other day services. Some things we hope to see in the future are:

- First and foremost: Choice in how we spend our days.
- Support for people with developmental disabilities to own their own businesses.
- Support for people to locate jobs based on their skills. This is called customized employment.
- Support for small, site-based day centers that are close to where people live and on bus lines.
- Development of innovative programs that are integrated into the community, allow people to be self-directed, gain real skills, and earn money. Examples of these options include: art studios, bakeries, florist shops, and other small businesses.
- That people's days will be totally flexible based on their needs and interests. Some people want to go to a center a few days a week, work part-time, take a class in the community. Supports need to be flexible so we can "mix and match" our activities and do the things we want to do.
- The availability of Medicaid funds to help people who need significant supports to work. We'll need to advocate on a national level for this. Our belief is that if our government is willing to pay for us to be supported in day programs, why not spend some of the same funds to help us work?

- Encourage organizations that support us to be a model for others by hiring us for jobs that we can do within their organizations.
- Significantly expand opportunities for included community service and volunteerism for people with disabilities. Many of us can and want to serve in our communities, and there are many community opportunities and national and state service projects that we can be a part of. It is a great way for people with disabilities to contribute to their community, make great connections, meet new friends and learn important job skills.

3. Some important legislation and issues that SANYS believes should be passed or addressed in the 2014 Legislative Session

Legislative Bills

- **Nurse Practice Act:** The Governors proposal to amend the Nurse Practice Act so that direct support professionals, under supervision of a nurse, can perform necessary medical supports in non-certified settings. This change is an important part of the development of individualized and self-directed supports.
- **Workers with disabilities Tax Credit Program (A.8492-B/S.49646-D)**
- **Disability History Curriculum (a.2006-A)**

Critical Issues

- Advocate for all funds saved by OPWDD's transformation activities stay within OPWDD's budget for other purposes. OPWDD needs every dollar possible to 1) support the needs of people who are currently in crisis and those who have been waiting for new services and 2) support the varied costs of transformation that must be considered as OPWDD creates opportunities for smaller, more integrated settings.
- A Cost of living increase for direct support professional staff is needed so that we can keep and continue to hire caring and capable people to support us. They deserve a living wage

The above statements represent views of the board of directors and many members of the Self-Advocacy Association of NY State. For more information please contact: Steve Holmes, Administrative Director at seholmes@sanys.org or call 518-796-8769.