New York Self-Determination Coalition

[www.nyselfd.org](http://www.nyselfd.org/)

Comment on Governor Cuomo's Proposed 2014-2015 Budget

The New York Self-Determination Coalition (NYSelfD) is an all-volunteer group of parents of people with developmental disabilities. We promote self-determination for people with disabilities by training and mentoring parents, and through advocacy.

What does self-determination mean in the day-to-day lives of people?

      Having control over daily activities: paid or volunteer work, continuing education, recreation

      Choosing support: family, coworkers, friends, support staff

      Deciding where to live: an apartment with a roommate, a house with friends, alone

      Being able to set the rhythms of your day: what time to eat, when to go to sleep

      Letting people with developmental disabilities, and their circles of support control their budgets and choose the services and supports that best meet their needs

NYSelfD strongly supports the Governor’s recommendation to expand the exemption to the Nurse Practice Act to people with developmental disabilities receiving services through OPWDD.

This provision is the critical change in policy that will allow people with developmental disabilities to truly be part of their communities. Currently, medications and other services prescribed by a physician must be administered in OPWDD certified settings. When this expansion is in place:

A 24-year old woman would be able to work in the cafeteria of the Community College, even though she needs a reminder to take her seizure medication during her shift.

A 30-year old man will be able to attend a night baseball game, because his support worker can help him with his asthma inhaler.

A 29-year-old will be able to share an apartment with a friend who also has disabilities, and their support staff can assist them with their medication regimens.

The Supreme Court’s 1999 Olmstead decision requires that states provide services to people with disabilities in the most integrated setting appropriate to their needs.

Closing large institutions is just the beginning. In order to fulfill the mandate of Olmsted New York State must approve the expansion of the Nurse Practice Act.

Maggie Hoffman and Susan Platkin, members

New York Self-Determination Coalition Advocacy Committee

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Time sensitive, please read

Hello All,

Governor Cuomo’s Executive budget came out last week, and we were happy to see that he supports expanding the exemption to the Nurse Practice Act to direct care staff for everyone getting OPWDD services.

What does this mean?

Under Olmstead’s mandate -  that people with disabilities must get services in the most integrated setting - the state is planning to close developmental centers and workshops, so that everyone can live, work and play in their communities.

But true integration is currently not possible for people who need assistance taking their medication, as the current law states they can only get this support while they are in an OPWDD “certified” setting. Unless the Governor’s proposal is supported by the legislature, very few people will be able to choose a self-directed life.

This is a tiny item in the budget, but has huge impact for people using CSS and other individualized services, and you can help!

Please take a look at the attached remarks we submitted to the Joint Legislative Budget Hearing on Health/Medicaid. If you agree and are willing to write an email, here’s a sample letter and contact info.

Sample letter:

Dear Assemblyperson or Senator. . .

I am writing to support Governor Cuomo’s call to expand the exemption of the Nurse Practice Act to direct care staff supporting everyone receiving OPWDD funded programs and services (2014-15 New York State Executive Budget, Health and Mental Hygiene, Article VII, Part D).

Give your name and a sentence about your child.

Tell a story about how being able to work, volunteer, got to school, be with friends, live in the community can only happen if direct support staff are able to assist your child in taking medication, using asthma inhaler, etc.

Thank them for their support.

Here’s where to send your emails:

To be part of the public comment on the budget, comments must be submitted by close of business on Friday to:

 Carole Luther, Legislative Assistant at luther@nysenate.gov

 (Staff for Sen. DeFrancisco)

In the next few weeks, please contact:

Aileen M Gunther (Chair, Mental Health Committee/Assembly) at GuntheA@assembly.state.ny.us

 Richard N. Gottfried (chair, Health Committee/Assembly) at GottfriedR@assembly.state.ny.us

It’s also helpful to send a copy of the email to YOUR New York State representatives in the Assembly and Senate. Here’s how to get their contact info:

Find my Member of the Assembly....  <http://assembly.state.ny.us/mem/?sh=search>

Find my Senator ...  <http://www.nysenate.gov/contact_form>

It would be great if you could blind cc. us on your emails.

Any questions, don’t hesitate to contact us.

Thanks,

Maggie Hoffman

Susan Platkin

New York Self-Determination Coalition

And some letters sent by parents in response to our call:

This communique is in support of Governor Cuomo's call to expand the exemption of the Nurse Practice Act to direct care staff supporting everyone receiving funded programs and services (2014-15 New York State Executive Budget, Health and Mental Hygiene, Article VII, Part D).

I'm the proud mom of twenty-two year old Luke, who, in spite of significant Developmental Delays is thriving in Cultivating Dreams, a unique endeavor I developed and launched under the auspices of CAREERS For People With Disabilities. Cultivating Dreams provides as much support as Luke and his buddies appreciate to enable them to focus on meaningful work and community interaction.The focus of their day is borne from their interests, talents and passions and if their happiness is any indication, we are on to something big. After all, they want what we each do: a job with meaning and purpose, a social life and housing. Watching them step out into our local community is courage in action, making the sky the limit for those too often secluded from life's events.

Twice daily, Luke takes Keppra, an anti seizure medication, which he'll be on for life. We are grateful the medication has kept Luke seizure free for two years with every hope for a completely seizure free life - **as long as he takes his medication regularly.**

As Luke pursues a life of independence, his next dream is to live in his own house with a few buddies.  It is imperative that in whatever setting turns out to be the best one for Luke, the support staff must be able to administer his medication in the morning and evening. Though he boasts many skills, responsibility for his dosage rests on a qualified staff member. The opportunity to live a fully independent life that is right for Luke can't happen unless staff oversees his daily medication.

Unless you live this life directly, it's hard to comprehend the full impact of this one act. Allowing for staff to administer medication is the difference between a young adult's ability to live life to the fullest rather than be restricted due to something so easily remedied.

On behalf of Luke, we thank you for your support. When you're out in the community, be sure to say hello to Luke; he's the one with the huge grin on his face.

Warmly,

Dear ,

I am writing to support Governor Cuomo’s call to expand the exemption of the Nurse Practice Act to direct care staff supporting everyone receiving OPWDD funded programs and services (2014-15 New York State Executive Budget, Health and Mental Hygiene, Article VII, Part D).

My daughter, Sarah is 12 years old and has Down syndrome.  Since her participation in the Early Intervention Program, I have worked closely with agencies including my school district in having Sarah included in her community. At 12, what that means for Sarah is she rides the regular yellow school bus with the children in her neighborhood and attends weekly hip hop dance classes at her local community dance studio.  Sarah when she transitions from school to post secondary adult life will undoubtedly pursue a Consolidated Support Services plan based on self-determination.  This will enable her to "live, work and play" in her community.

Daily, I give thanks for Sarah's good health.  I also empathize with people who need the daily assistance of medical professionals.  I strongly believe that an person's right to "live, work and play" in the community can only happen if direct support staff are able to assist people who require medication.

I thank you for your attention and hope you will support the rights of all individuals to "live, work and play" in their communities.

Sincerely,