

Elizabeth Dellureficio

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2/19/19

To whom it may concern:

Here is my testimony for the Manhattan Budget Forum and the State Budget. My grave concern is the danger that the CDPA program is in.

I am a Manhattan resident living for the past 30 years on the Upper West Side. I live there with my 21 year old daughter Nika, and my husband Bob. Our daughter Nika has cerebral palsy and epilepsy. She requires total assistance in all daily activities: eating, bathing, dressing, transferring to wheelchair, etc. Despite these challenges our daughter is a productive member of society and a delight. Nika is employed part – time at two special needs schools in Manhattan. She is an Empowerment teacher, sharing her experience as a disabled person with other children and inspiring them to live out their dreams.

Nika thrives in great part due to the CDPA program. CDPA has been in existence for many years. It allows us to hire the aide of OUR choice and provides enough hours to help Nika stay in the community. Our aides get paid \$15 an hour and the work can be challenging. We are so grateful to our aides, and so grateful we can hire and train and manage who we want. That is crucial to ensure that Nika's needs are met. Without this program many people would be forced into nursing homes at a cost far greater than the program while also putting the aides out of work. There are 70,000 consumers who use the CDPA program and 100,000 employees in the state.

Governor Cuomo has added proposals to his state budget that would effectively kill the CDPA program. He is suggesting:

--- To limit the amount that the FI's get reimbursed to a monthly capitated fee of \$100. Our daughter gets 12 hours a day of CDPA and she and other high needs consumers would not be served by FI's since the administrative costs of serving such high needs clients would mean FI's would not accept such clients.

---Also, Governor Cuomo's budget would reduce FI's eliminating 9 out of every 10 FI, with the ultimate goal of moving to one FI. This would effectively create a monopoly and ruin CDPA.

---Also in this proposed law, if the Federal Government does not approve the new version of this law, they have the right to cancel the CDPA program. And the Gov. proposals allow the Commissioner of Health to end the program whenever he/ she wants.

For more information on why the Governor's proposals must be rejected please see cdpaanys.org.

Please oppose these devastating cuts to the CDPA program. They make no sense from either a financial or moral standpoint.

Thank you,
Elizabeth Dellureficio

State Budget Forum
March 2, 2019

Hi my name is Jacqueline Chambers, Mother Of Khloee Lauren Chambers.

(CDPAP)..has enhanced the Quality of life for My daughter KHLOEE and myself. It has enabled her to maximize her Potential and be safely integrated into our community.

Khloee has been in the CDPAP program for 20 years. The reasons CDPAP works: It give parents & families, The Liberty To Seek, Hire and terminate employment. I, as her legal guardian, Provide the skills needed to perform their job and give assistance when needed.

This program has permitted me to maintain employment for 30 Years.

While giving me a Peace Of Mind knowing Khloee is safe and secure In our home with a family member or Personal Assistant OF MY CHOICE.

Prior to me making My Decision to move Khloee's Case From The Traditional Home Attendant Agency Into the CDPAP PROGRAM.

I encountered a Very hostile incident where the home attendant was stealing from our home. I reported the incident to the agency they sent an Investigation agency to follow up on my claim to no avail.

The CDPAP program permits me to hire People who will bring Compassion, Love and the gentleness, and kindness, (humanity side), And the skills needed to Provide the Absolute Best Care Possible For khloee, (this also includes the ability to administer Khloee's (medication)...if it were not for the CDPAP program, Khloee would require a nursing level of Care.(which would be more costly.)

The CDPAP PROGRAM WORKS...

how do I know for certain? because I personally train the personal assistant thoroughly for Khloee. I am comfortable leaving our home to go on vacation, handle errands, work etc. It's essential in having consistency, and Stability for Khloee.

I would like to conclude by saying we Need the CDPAP program, As we Need Oxygen to Breath.

Thank You for your time.

Mary Somoza

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March 2nd 2019

Distinguished Senators:

My name is Mary Somoza and I am the mother of four adult children which includes my twin daughters Alba and Anastasia both of whom have cerebral palsy since birth. My girls need assistance with all aspects of daily living, they cannot get out of bed on their own, shower, dress themselves, and need bathroom and feeding help throughout the day. They cannot open a door on their own, or do many of the things we take for granted and do automatically. I hate to be so specific, but most people do not have an idea of what their lives are like, or how much they depend on assistance from others.

And yet, they both lead full lives in our wonderful city. Both work, and pay taxes. Regardless of their disability, something they could not do without the help of the personal care assistants who help me take care of them. I spent many years using traditional agencies designated for me by Medicaid. Those were the most difficult and stressful days. The hours were fixed which meant that most afternoons and evenings I was on my own, out of the blue new aides would show up to cover a shift, total strangers, some whom did not speak the same language as I did – and I speak five languages – so you can imagine what that was like.

We were moved into CDPA when my daughters were twelve years old, they were the first children to be accepted into the program. It changed our lives. We got to recruit our aides, interview them, try

them out, and have control over the hours assigned to us. Many of our aides stayed for years, making daily life so much more livable for us families. And, it saved the government money as it cut out the middleman and even though it was more work for us families, the quality of our lives changed dramatically and our aides stayed with us so much longer.

I don't know who is advising our Governor to do what he is doing. I have been an appointee of the Governor's to the Advisory Council of the Office of People with Developmental Disabilities since 1991 originally appointed by Governor Mario Cuomo. None of us were asked to "advise" our present Governor on our perspectives of this draconian proposed legislation. It came out of the blue, but I do know that it is a part of the bigger plan to force our most vulnerable population into managed care where the government and the legislature will have no oversight. It will be privatized care. It will be a return to the days of Willowbrook as services are cut and denied by heartless organizations only interested in profit and not the value of human lives. Who would have thought a Democratic Governor would do this? I have repeatedly tried to contact him with long written reports, to no avail. They are intent on rolling over us. And the legislature is our only hope now to stop this. I urge you to look into the eyes of your constituents with disabilities and promise us you will not abandon us.

In the interest of time, this is a short summary. I will submit longer testimony via email.

Respectfully submitted,

Mary Somoza -

Accompanied by Alba Somoza, 35- year old young woman with cerebral palsy, spastic quadriplegia

Anastasia Somoza – 35- year old twin sister of Alba, also with cerebral palsy, spastic quadriplegia,

Annie St. Martin – Personal Care Assistant to Somoza twins

Alexa Valdez – Personal Care Assistant to Somoza twins

SERVICES FOR PEOPLE WITH IDD

My name is Meri Krassner and I want to make the case for investing in infrastructure, but not bridges, roads and tunnels – the infrastructure that keeps families going. We pay lip service in this country to caring about families but we do nothing at all about it, and in fact, it is often the first place politicians go to look for cuts in government services. For families of people with Intellectual and Developmental Disabilities it is the programs and more specifically the Direct Support Professionals who hold families together, they are the infrastructure. DSPs are trained by agencies to take care of those with IDD and their day may include activities of daily living, medication dispersal, travel training, toileting or help with socializing. They work with a range of people; those who need only light support to those who need help with every single activity of daily living like my son. They are the staff at Day Habilitation Programs, Recreation programs, Residential services, Respite and Home Care. Without these programs and workers, I would have to quit my job to stay home with my son. I'd no longer be a taxpayer. DSPs would not have jobs and the result would be less people working, people whose wages go right back into the economy through spending and taxes.

I am very skeptical about the reasons DSPs are paid so poorly. I think it is no coincidence that the overwhelming majority of DSPs are women, and often women of color. Is it a coincidence that these wages are so low, is there some correlation between who is doing the job, who they are doing it for and what the pay is? These are jobs that cannot be automated, and they can't be outsourced. This should make them more valuable, a bedrock of the economy but these jobs must not be 'important enough' or the job would come with a living wage.

Why isn't this wage gap part of the Women's Agenda? Why aren't these people on the economic radar? Where is fiscal equity? These jobs are crucial to keeping families together and the children alive when their parents are gone. These jobs help families, often headed by women who are doing it alone and it helps the individuals – these workers are the glue that keep families intact. Better pay also benefits the families of those doing the work. DSPs children should not suffer because their parents have to work two jobs to keep a roof over their head. That puts both their families and our families at risk. This is bad policy.

It's one thing to talk the talk about valuing people but it is hollow without putting money in the budget to bring these jobs up to a living wage. Once upon a time DSPs earned more than 40% over minimum wage – but that is no longer true. Now that the minimum wage is \$15 why would anyone choose this demanding work with the Justice Center handing over your shoulder when you can stack

Meri Krassner

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SERVICES FOR PEOPLE WITH IDD

shelves at Target and go home at night. Those jobs don't bring the responsibility and burden of some vulnerable person's care.

DSPs should be able to support their families with this job without having to hold another job, overstressing themselves and putting people at risk. Better pay would help with recruitment and retention and also signal that taking care of vulnerable people is a noble job. Paying lip service to these ideas doesn't pay the bills, and doesn't honor the importance DSPs have in keeping families intact. The Women's Agenda should include the needs of women who have disabled children, their need for support. The Women's Agenda should address the rights of the women who are Direct Support Professionals – the right to be paid a living wage.

This is human infrastructure. Supports and services and the people who provide them keep families intact, keep society functioning. It is crucial that the budget reflect this. Including the next two #BFair2DirectCare installments in the budget, making real Cuomo's promise is the very least that should be done for fiscal equity.

Without these raises all the planning to transition our loved ones to Managed Care will be an exercise in theory. DOH plans are underfunded, underdeveloped and not well thought out but it won't matter if there is no one to deliver the services all this is being designed around.

Meri Krassner

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Manhattan Delegation

Saturday, March 2, 2019 6:16 AM

March 2, 2019

Thank you for this opportunity to present my written testimony regarding the NYS Budget. I am the father of two young adults who get services from the Office for People With Developmental Disabilities (OPWDD).

SUMMARY

My concern is people with Developmental Disabilities in New York State, and the oversight of the complex system which delivers the services they need. My goal is the creation of an ever-more transparent and accountable system. My request is funding for Information Technology systems which allow all of us to see what the system is doing. This IT-enabled visibility is required to maintain and improve the service delivery system.

DETAILS- Antiquated systems and Tech-Debt

Today, OPWDD lives in an antiquated world of incompatible and inaccessible collections of data. Decision-makers in the past have operated with positive intent, but perhaps with insufficient long-term vision. Specifically, for many decades OPWDD concentrated on attempting to serve the immediate needs of the clients, and meanwhile neglected to make investments in technology infrastructure. I work as a manager of IT systems, and the term of art is "accumulated technical debt", usually abbreviated to "tech-debt."

Accumulated tech-debt is a problem-- and an embarrassment-- for almost every organization which handles large amounts of data. Tech-debt eventually brings progress to a complete halt. One of the text-book consequences of tech-debt is that the organization becomes opaque to itself, and can no longer tell whether changes in policy and procedure are making things better or worse. This is exactly what we see today at OPWDD.

Reducing tech debt to manageable levels requires substantial investments to purchase updated systems and hire skilled professionals to make them work. Organizations consistently "mis-under-estimate" the time and dollars required.

DETAILS- Investment needed

The situation at OPWDD would make a great academic case study. We can see the impact of insufficient investment on operational capacity and the ability for the system to transform. And it is somewhat amusing that when OPWDD needs vital data, they do not search a database, but instead rummage around in a file cabinet. But it is not academic for me, nor for the family members of the 130,000 individuals with DD in New York State. The impaired "operational capacity" has a direct impact on the lives of our loved one.

I am a member of SWAN, the StateWide Advocacy Network for people with developmental disabilities. We ask that you provide OPWDD with the funding required to provide periodic, detailed reports on service approval and service delivery. Eventually, that reporting should be through a self-service portal, such as the one that the Department of Health is building, the Medicaid Analytics Performance Portal (MAPP). Please combine the funding with a mandate that this OPWDD data & reporting project meets with the Advocacy Community monthly, to provide updates on their progress and get feedback from families and from the independent watch-dog organizations such as Disability Rights New York (DRNY). Having periodic participation by the legislature would also be helpful.

DETAILS- Legislative action

Attached to my testimony you will find the "SWAN Requests" from March 2018. This was reviewed with DoH and OPWDD in Spring of 2018, and all parties agreed to a "crawl/walk/run" strategy for making progress on the eleven requests. We made progress at first, with updates on roughly a monthly cadence and the delivery in August 2018 of data from the year 2016. But in the six months since then, there has been zero apparent progress. Competing priorities have consumed the attention of the managers and IT professionals at OPWDD and DOH.

The crawl has turned into a stop. Please provide the NYS agencies with the message that this is a top priority, and provide the funding they need to make it a reality. Today we have an opaque delivery system going through a major transformation. Are things getting better, or worse? The Advocacy community cannot tell, and the leaders at OPWDD cannot tell either. We are forced to rely on anecdotes and small sub-sets of the population. Narrative is vitally important. But to make wise decisions, we need to have fast-feedback about the impact of our choices. We do not have that today. **The system is opaque to itself. That needs to change. Please help.**

-Jim Karpe

Father of two young adults with I/DD

SWAN Steering Committee member, www.swannys.org

516-655-2713

*"We must learn to live together as brothers
or perish together as fools." -MLK, Jr.*

Attachments:

- SWAN Requests from March 2018.
- SWAN "leave-behind" update from February, 2019.
- DRNY Testimony from February 14, 2019. Note the reliance on anecdotes, with data limited to a couple of small populations which are "inspectable"-- for example, the count of number of individuals who are in out-of-state facilities.



Accurate data needed for future planning

Problem

OPWDD's future planning is suffering due to past under-investment in IT (Information Technology). OPWDD directs the flow of \$8 Billion in funding each year to support the health and well-being of one-hundred thirty thousand people with Intellectual and Developmental Disabilities (I/DD). OPWDD has always put their clients first, and therefore have underfunded their own infrastructure. As a direct result, even basic measurements now require substantial manual effort to compile, and are rarely performed. We are "flying blind" as the system transitions to Managed Care, from the current fee-for-service.

The system is opaque to itself. The vital rate-setting for Managed Care is getting calculated based on historical service delivery, rather than on the need for which services were approved. Delivery is an inadequate measure, but according to data experts within OPWDD they don't have search-able electronic records of what was authorized. In recent years, lack of system capacity resulted in the I/DD population suffering with unmet needs. We object to using this historical under-delivery as the basis for future funding.

Solution

The proposed solution is a modest investment to improve the existing Medicaid Analytics Performance Portal (MAPP). We want MAPP to bring in information on the I/DD population, and then provide families and the advocacy community with appropriate access, including the ability to generate diagnostic reports about how people are being served. An investment of \$10 million in IT over the next three years could make the difference between success and failure for the Managed Care transition.

The money would flow to the IT teams at Department of Health and OPWDD, so that they can achieve what SWAN requested in March 2018, as agreed to by both DOH and OPWDD <http://swannys.org/2018/06/09/mapp-requests-from-swan-3-11-18/>. Late last year we had indications from the Governor's Office that they were also supportive of this effort. However, the initiative has not been funded and there has been little progress to date. SWAN was given a manually created extract of 2016 data, and recently we were told it

"cannot be moved to a production basis without significant development."

We are looking to the legislature to provide leadership on finding funding for this development. The data will provide an accurate picture of OPWDD services and score a victory for transparency, accountability, and appropriate oversight, all in the cause of helping the vulnerable community of people with developmental disabilities. We are not aware of, nor do we anticipate, any opposition to this initiative.

SWAN: The Statewide Family Advocacy Network of New York State ([SWAN of NYS](#)) is dedicated to advocating for individuals with Intellectual and Developmental Disabilities. We are an independent coalition of families and guardians of people with Intellectual and Developmental Disabilities.

Caring for our loved ones is our life-long commitment.



MAPP requests from SWAN

Underlying principles

We believe that everyone involved in the New York State Medicaid system has the common goal of delivering services as effectively and efficiently as possible. Our suggested improvements to the Medicaid Analytics Performance Platform (MAPP) will provide accurate reports on services used by people with disabilities which can have a direct positive impact on the quality and efficiency of the NYS Medicaid system.

Product Vision

From the perspective of parents and advocates of people with Intellectual and Developmental Disabilities (I/DD):

- MAPP reports can provide transparency into what the Medicaid service delivery system is doing right, and where improvement is needed.
- MAPP reports will allow us to drill down into sub-groups, to the extent allowed by privacy laws. To comply with HIPPA, these sub-groups will need to be anonymized ("remove identifying particulars for statistical purposes").
- MAPP will allow advocates to send "blind" messages, so that individuals can contact advocates to help resolve issues.
- MAPP will allow properly authorized people to generate a non-anonymized report on an individual.

Information for I/DD Advocates

These are listed in *rough* priority order. Priorities will most likely change over time.

As Advocates in NYS for Individuals with Intellectual and Developmental Disabilities, we want to have:

1. Reports on the ratio of "services delivered over services approved", so that we can understand where system breakdowns are taking place.
2. Service delivery reports broken down by geography (county-level, zip code), provider, acuity, service type, provider type (State or Non-Profit agency); so that we can drill down into details about what is working and what is not.
3. Reports on approvals and authorizations for waiver services generally as well as specific services, including the ratio of approvals to applications, time from application to decision; so that we can monitor the intake process.
4. Reports on residential supports, including specific categorization of "priority" categories, prior and current housing situation, date of request & approval & delivery, in addition to geography, provider, acuity, etc; so that we can determine where there are adequate services and where there is unmet need.
5. Approval reports broken down by same criteria as service delivery reports, and in addition based on ethnicity, and language preference; to detect any inadvertent systematic problems.
6. Reports which compare current performance to past, with adjustable time scale (months, quarters, years); to spot both negative and positive trends.

7. Ability to generate and send messages to sub-groups. Advocates can send messages to individuals, the professionals serving them, and their family members to tell them how they can get in touch with an advocacy group to bring issues to the surface and get them resolved.
8. Ability for an individual or authorized family member to generate a standard, detailed, non-anonymized report on their individual of interest; so that we can provide an on-going feedback loop to the service providers, and easily monitor the quality and accuracy of MAPP data and reports.
9. Reports on "pre-review" service delivery—that is, based on initial submission of billing requests from providers; to have early detection of potential positive and negative trends in provision of services.
10. Reports on review outcomes versus pre-review requests; to monitor the review process.
11. Reports on wait lists which are maintained by OPWDD, DOH and by any other entities, broken down as described for other reports, including length of time on list; to verify that the wait lists are fair and equitable.

Data Details

Before MAPP can produce reports, it must have data. Currently, relevant data sources regarding I/DD are not included.

- Choices- the application that Provider personnel use to track individuals with I/DD
- Tabs- used by OPWDD personnel to track Providers, programs, and program enrollment.

Since we do not have good information about the structure of the data environment at OPWDD, it could be that there are other vital sources in addition to those listed above. There might be a single underlying database which feeds into the systems which providers and OPWDD personnel interact with. MAPP personnel will of course need to consult with people who have expert knowledge of the OPWDD systems. This might be a good place to start:

[https://opwdd.ny.gov/opwdd_resources/procurement_opportunities/Current TABS Data Exchange](https://opwdd.ny.gov/opwdd_resources/procurement_opportunities/Current_TABS_Data_Exchange)

Vital data elements include TABS ID, Medicaid ID, DDP2 assessment information as listed starting on page 38 of the Data Exchange document, and the CAS equivalents when those become available. Also the service needs as listed on pages 42-44. There are many other data elements needed to create the desired reports, such as: overall acuity score, behavioral score, Vineland score, diagnostic category, application date, LCED approval date, residence type, agency code, ages of parents, Self-Direction budget application and approval dates, PRA.

We want MAPP to have excellent data governance. Specifically, the vital data elements in MAPP must:

- be adequately detailed & accurate (data standards),
- have agreed upon meanings (business rules),
- get periodically reviewed to ensure it is still accurate (data maintenance).

MAPP has an opportunity to reduce the elapsed time between service delivery and reporting. This can be done by bringing in the initial billing submissions from Medicaid providers. The compelling advantage is that those submissions are available months earlier than the reviewed and approved payments. Some portion of those bills will be rejected upon review, so it will be vital to differentiate between the "pre-review" request and the reviewed outcome.

To monitor the various wait lists, MAPP will need to intake those wait lists and match them with other records through use of standard matching methods, such as ID #s, names and addresses, email, etc.



DISABILITY RIGHTS NEW YORK

 www.drny.org  mail@drny.org  518-432-7861

February 14, 2019

The Honorable Aileen Gunther, Chair
Assembly Standing Committee on
Mental Health and Developmental Disabilities

The Honorable David Carlucci, Chair
Senate Standing Committee on
Mental Health and Developmental Disabilities

Dear Chairpersons,

Thank you for the opportunity to address your committees concerning the sufficiency of access to developmental disability services and supports, in the context of the 2019-2020 Executive Budget Proposal. Disability Rights New York (DRNY) is an independent, non-profit agency, authorized under federal and state law to be the protection and advocacy (P&A) system for New Yorkers with disabilities. As part of its role as New York's P&A, DRNY has an interest in ensuring that people with disabilities receive the support they need to live independently in their communities.

We applaud Governor Cuomo's commitment to increase funding to the Office for People with Developmental Disabilities (OPWDD) programs, particularly for programs supporting community housing and independent living. Likewise, we applaud the Governor's funding to support provider costs associated with the movement to a \$15 an hour living wage. However, DRNY has serious concerns regarding another aspect of the Governor's 2020 Budget Proposal: namely, the transition to managed care for delivery of services and programs for people with intellectual and developmental disabilities.

While Governor Cuomo's Briefing Book calls last year's transition of care coordination to regional Care Coordination Organizations (CCOs) "successful," implementation is incomplete and challenges remain. Nevertheless, OPWDD and the New York Department of Health (DOH) are recklessly moving forward to implement managed care as soon as 2020.

To that end, the DOH and OPWDD recently published a proposal on the requirements for the new managed care organizations (MCOs), entitled "New York State Medicaid Managed Care Organization I/DD System Transformation Requirements and Standards to Serve Individuals with Intellectual and/or Developmental Disabilities in Specialized I/DD Plans – Provider Led (SIPs-PL) ("Plan"). We appreciate DOH and OPWDD's commitment to providing people the support they need to live independently in the community. However, the current plan for transition to managed care is short-sighted and extremely deficient. Implementing the Plan as it

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currently stands will lead to financially weak MCOs; limit services provided to individuals with disabilities; and impose higher costs on the state as those individuals who lack needed community-based services are forced into institutions.

A letter detailing the full range of our concerns was submitted to OPWDD and DOH on October 3, 2018. However, we have little confidence our observations were heard as the transition to managed care is similar to a runaway train. We are therefore grateful for the Legislature's willingness to consider funding measures to address the following issues.

Addressing the Existing Shortage of Services and Workers across New York State

DRNY strongly supports increased funding and focus on supporting direct support professionals who deliver services to individuals with intellectual and developmental disabilities. The current scarcity of these workers is a major problem across the state. DRNY has received numerous complaints regarding individuals who are eligible for OPWDD services, but cannot obtain them due to a lack of staff and providers.

Consequently, individuals with complex needs are often forced to receive services in institutional settings such as hospital emergency rooms, nursing homes, intermediate care facilities, and psychiatric centers. One of our clients, a 16 year old with autism from Queens, was for years unable to receive any OPWDD services that could have helped to mitigate his complex behavioral needs at home. Because no providers were available to provide the services for which he was approved, his family was left with no choice but to admit him to Elmhurst's psychiatric hospital due to his self-injurious and aggressive behaviors. Our client lived at Elmhurst for five months in seclusion, without any education or programming and was repeatedly tied down by staff. Our client had no psychiatric issues which Elmhurst could treat and his clinicians readily admitted he was only at Elmhurst because of his lack of OPWDD services.

Even individuals without complex needs are forced to go without any community services despite being approved for them. Individuals and families regularly contact DRNY for help in obtaining services they are approved for, but cannot obtain. Such services include respite, community habilitation, supported employment, and day programs. There are several explanations as to why individuals are unable to obtain these needed services including: low pay for DSPs, the usual part-time nature of the job with little to no benefits, and individuals and families needing services around the same times particularly after school and/or work and on the weekends

In our experience, an individual may go for many months or even years before receiving essential services even though they are approved to receive them. For example, another client aged out of the Wildwood School in Latham in 2015. However, he was unable to obtain a day

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program for two years after graduation despite being approved for this service. In addition, he was unable to receive community habilitation or respite despite being approved for these services for over a decade. Consequently, his single mother was unable to work and instead had to supervise him because he could not care for himself. The OPWDD case manager revealed that because our client lived in public housing and was a large young nonverbal black man with autism, and no one was willing to work with him under the prevailing rates.

The lack of direct support professionals is even worse in rural areas and there is no plan in place to address this. In many rural counties there is only one service provider who offers in-home supports and services such as respite and community habilitation. Even worse, according to OPWDD's provider directory, there is presently not a single agency that offers in-home services in Hamilton County. Even in rural counties where there is at least one service provider, the waiting list for services is long. There has been absolutely no information from OPWDD or DOH regarding how the Plan will ameliorate staffing shortages.

None of these issues will be resolved by managed care. In fact, OPWDD's Plan does not provide realistic solutions to the current inability to access services in rural communities. Instead, OPWDD's plan is that when a service cannot be accessed in a county like Hamilton, a managed care organization ("MCO") must contract with a provider in a neighboring county. If this is still insufficient then the MCO should contract with a provider in another Developmental Disabilities Regional Office ("DDRO"). The Plan gives the example that if someone lives in Rensselaer County and cannot obtain a service from a provider within that DDRO region, the MCO should just contract with a provider in Sunmount (the Adirondacks) or Hudson Valley to provide the service. This proposal is wholly unrealistic as it assumes that a worker would be willing and able to drive two or three hours each way, unpaid, to deliver in-home respite to someone in a neighboring county or region for close to minimum wage.

Before the transition to managed care occurs, OPWDD and DOH must increase their service delivery capacity and ensure that each county has at least two providers that can deliver services within a maximum of 60 days of the individual being approved.

Lack of Clarity Regarding the Role of the DDRO and DDSOs under Managed Care

Despite repeated inquiries by DRNY, it is unclear what the future role of OPWDD's Developmental Disabilities Services Offices ("DDSO") will be when managed care is mandated. Historically, the DDSO was always the provider agency of last resort for people with complex needs. When individuals with complex behavioral needs, medical needs, and forensic backgrounds are unable to receive services from non-profit agencies, the DDSO often is the only entity able and willing to provide care and treatment. While the Plan states that DDSO will continue to operate under managed care, it is silent as to what this will actually look like. It is

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unlikely that a managed care organization would want to contract with the DDSO for services. DDSO services often more expensive because employees are unionized State workers who are paid a much higher rate than their counterparts who work for non-profit agencies.

This is concerning for two reasons. First, it could result in the privatization and loss of thousands of State employees who are skilled direct support professionals, thereby exacerbating the current staffing crisis. Moreover, it could put DDSO's out of business. Since the DDSO provides services to those no one else will serve, numerous individuals with complex needs will be left without care.

Managed Care Organization's Inadequate Capitation Rates

Managed care organizations (MCO) will be incentivized to deliver fewer services to their enrollees than the current system. This is because within 24 months after managed care is mandated, reimbursement for services will be paid at a capitated rate. This payment model means that an MCO will receive the same reimbursement rate for all of its members regardless of the services they receive. Consequently, individuals who have complex and intense medical or behavioral needs will be given the same funding levels as other individuals who have significantly fewer needs. The proposed inflexibility in funding levels will exacerbate the inability of these individuals to access needed services.

As already mentioned, even under the current rate system, individuals with the most complex needs are denied services they are approved to receive. For example, dozens of individuals at the remaining Developmental Centers are eligible for discharge with enhanced funding, but remain institutionalized. Similarly, over 200 adult graduates at residential schools are lingering in institutional settings even with enhanced funding. Consequently, if OPWDD eliminates enhanced funding through capitated payments, there is no doubt the number of people unable to access community based services will only grow, as will the number requiring institutionalization.

In New York's current managed long-term care system for older adults and adults with physical disabilities who need services like home attendants, the MCOs routinely offer members low hours of services with no basis, such as, in the experience of one colleague, a plan that offered a 75-year-old stroke victim who is paralyzed and incontinent only 8 hours per day instead of the 24 hours recommended by multiple doctors. Several plans have done indiscriminate across-the-board hours cuts with no individualized review and inadequate notice.

Likewise, according to Disability Rights Kansas, when managed care was implemented in Kansas, "it became a constant battle [with managed care companies for individuals with

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disabilities] to get what you're entitled to . . ."¹ Services were cut substantially at the sole discretion of managed care organizations. For example, a woman who had suffered a traumatic brain injury had her home aides cut by 10 hours a day by her managed care company, despite the fact that her physician certified that she needed the additional support.²

Finally, the Plan lacks any details regarding how capitated rates will be set other than to say that they will be "actuarially sound." It is shocking that the Plan lacks any details regarding the rates and how they will be set. Given the already dire situation for people with complex needs to access community services, using these rates as a basis for capitated rates will only exacerbate their inability to access services. Since these individuals with high needs will be a drain on a MCOs budget, they will be highly motivated to remove them from their responsibility by recommending institutional settings like nursing homes.

Financial Viability of MCOs

The Plan raises concerns regarding the long-term financial viability of managed care for people with development disabilities. Multiple managed long-term care plans in New York State for older adults and adults with physical disabilities who need long-term care services have closed or are in danger of closing due to financial issues, leading to disruption in member care. OPWDD's managed care proposal is based largely on the model developed by former Medicaid Director Jason Helgeson, who first implemented managed care in Wisconsin. After managed care was implemented there, three MCOs became bankrupt and three others were forced to consolidate due to financial issues. Given this track record it is likely that a similar outcome will come to pass in New York, inevitably disrupting the provision of necessary services and leaving less choice for individuals with disabilities and their families.

Repatriation of New York Residents in Out-of-State Institutions

There are currently more than 600 Medicaid enrollees living in institutions, primarily nursing homes, in other states. This includes children in pediatric units. Separating adults and children with disabilities by such long distances exacerbates the isolation already inherent in institutional placements. The State must provide funding and guidance to repatriate all of its residents and provide them with community-based supports and services in New York.

¹ Kansas Health Institute, [KanCare Not Working for People with Disabilities Advocates Say](http://www.khi.org/news/article/kancare-not-working-for-people-with-disabilities-advocates-say), (July, 7, 2015), accessible at: <http://www.khi.org/news/article/kancare-not-working-for-people-with-disabilities-advocates-say>

² Id.

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Conclusion

Access to needed services for people with developmental disabilities and their families in New York State is already dire. While OPWDD's managed care Plan is couched in language of improving access to services, it appears quite unlikely that this will actually happen. In addition, under a capitated payment model, managed care organization would have an incentive for people to underutilize services. Ultimately, this will result in an increased lack of access to community based services and increased institutionalization of individuals with complex needs.

OPWDD and DOH's current plan for the transition to managed care will have profound negative effects on individuals with intellectual and developmental disabilities. The State must conduct further outreach to stakeholders, and provide clarification, measurable outcomes, and further development of its proposal to expand and ensure access to necessary services for people with intellectual and developmental disabilities.

Thank you for the opportunity to submit this testimony. We appreciate your consideration and commitment to examining each stage of the transition to managed care and providing sufficient resources to ensure community services and supports are available for every individual with an intellectual and/or developmental disability and their families.

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