



## The Arc New York Statement to the Assembly Standing Committee on Mental Health and Developmental Disabilities

**December 6, 2018**  
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Chairperson Gunther and members of the Committee, thank you for giving me the opportunity to talk to you today. My name is Saundra Gumerove. I am the President of The Arc New York, and a special needs attorney and advocate. But, most importantly I am the parent of a daughter with intellectual and developmental disabilities (I/DD). Although Lauren likes to come with me to hearings such as this one, she was unable to attend today. I do have her picture so you can see why I am here today and why this hearing is so important.

As you may know, the Arc New York is a family-led organization that advocates and provides supports and services to people with intellectual, developmental, and other disabilities, emphasizing choice and community engagement. We celebrate a seventy-year history as advocates and service providers next year. With 51 Chapters across New York state, our organization supports more than 60,000 individuals and families and employs more than 30,000 people statewide.

People with intellectual and developmental disabilities are one of, if not the last, Medicaid populations to transition to managed care. The delay is reflective of the complexity inherent in supporting people with I/DD. We must remember that Lauren and her friends are not “patients,” she is not sick or elderly, as other populations that have transitioned to managed care may be. She and others with I/DD have normal life spans and are guaranteed a “life” under Olmstead. They are, and will be, part of their communities for years to come. They are not going away.

As much as 85 percent of the Medicaid spend for people with I/DD is for long-term waiver services as opposed to traditional medical costs such as a place to live, day programs, supported employment, etc. These services ensure that people with I/DD have a rich, full life, not custodial care. It is for this reason that existing models of managed care cannot be simply imported from other health care systems.

The implementation of managed care for people with I/DD is unlikely to significantly reduce Medicaid costs. However, we recognize that, if implemented thoughtfully, managed care does have the potential to enhance service coordination, increase access to preventive and acute care, and create payment methods that incentivize positive outcomes while preserving quality of life.

It is for these reasons that we, and our field as a whole, are prepared to partner with you in the transition to managed care, and to support thoughtful and proactive consolidation.

While there is a model for successful managed care transformation in the health care system, it is critical to recognize that the success realized by the health care field has been supported by appropriate funding to facilitate the transformation.

Hospitals and other traditional health care systems have received hundreds of millions of dollars in transformation funding. These crucial funds supported the cost of consolidating salaries and benefits, developing infrastructure and technology needed to successfully migrate to managed care, and allow for debt pay-downs and other savings, to free up funds so healthcare providers could become more nimble and develop innovative new models to meet shared goals. The OPWDD system needs the same support so that services can continue to be provided while preserving quality of life for people with I/DD. The goal must be to maintain quality of life, not merely cost savings.

Our field is expected – and prepared – to transform. However, we need your help. To date, we have not been supported by the funding necessary to successfully see that transformation through.

While the rest of the health care system receives regular increases under the global Medicaid Cap, it's been nearly a decade since our field has received a meaningful COLA. The attached COLA history for our field demonstrates that we have received only a .02 percent trend factor since 2010. This makes it impossible to maintain appropriate staffing levels and other services as costs rise.

We are glad to see that OPWDD policy now supports funding for auspice change. However, under the auspice change policy, those funds only cover mergers undertaken in response to urgent fiscal or quality needs. An alternate policy supporting voluntary consolidation could be used proactively to avoid crisis consolidation, but there is insufficient funding available to do so. As a result, we are limited to consolidating reactively, when providers are in dire financial crisis. In order to successfully move our field toward managed care, and achieve efficiency, OPWDD funding must support proactive auspice change.

To effectively transition to managed care, our field needs adequate transformation funding, reflective of the support the health care system has received to invest in IT, develop infrastructure and allow for flexibility.

We all want managed care to be a success. However, if our field undertakes the impending transformation in the current landscape, it is frighteningly likely to fail.

After a decade without any meaningful trend factor, providers are growing less and less capable of remaining financially viable. They are challenged to maintain their existing facilities and infrastructure, and they face an ongoing workforce crisis. While the need for residential placements continues to grow, providers are not in a position to consider development when they're unable to adequately staff for their existing needs.

The impact on people with I/DD and their families is devastating, and getting worse. I know, my clients have become desperate in seeking services and residential opportunities for their children. Parents in their 80s should not have to die for their children to receive services, and yes, that is what many are told.

Not-for-profit, OPWDD-funded provider agencies deliver about 90 percent of the day-to-day services for more than 130,000 people with developmental disabilities in New York state. Salaries for the nearly 100,000 Direct Support Professionals (DSPs) who provide these critical and complex services are set at rates determined by the government. But, after years of funding freezes and sparse increases, our DSPs no longer earn a living wage. Provider agencies are competing for employees with fast food restaurants and big box stores and now Amazon, where workers can earn more and work less.

More than 14 percent of all DSP jobs were vacant in 2017. The staff turnover rate is 26.7 percent annually statewide. Some providers are functioning with program vacancy rates as high as 40 percent, and more than 10 million overtime hours were logged in 2017, as providers attempt to deliver needed services with minimal staff.

These challenges carry a huge financial cost for providers, and, in turn, for the state and our taxpayers. Providers statewide paid nearly \$50 million in overtime wages, and over \$100 million in estimated administrative and training expenses for new hires and employee turnover in 2017. Those costs would be better invested in paying a living wage that allows us to retain quality staff. Living wages, quality staff, staff retention equals better services for the people and families we serve, and, after all, isn't that why we are all here and why we all exist?

Without adequate funding to resolve our workforce crisis, our system of care for people with I/DD is at risk of collapse. Across the state, providers are unable to open new residential programs because they can't staff their current homes. Providers are being forced to relocate individuals to alternate homes on the weekends to accommodate inadequate weekend staffing. In some cases, providers have been forced to close homes, not for lack of need, but because they can't staff the location. After years in crisis, care options are dwindling, and parents are afraid that their children will end up in homeless shelters, hospitals or nursing homes.

Our Article 16 clinics are also in jeopardy. These clinics provide critical interventions, including psychology, psychiatry, behavioral, physical, occupational and speech therapies, medication management and dental care for individuals who cannot be served by a community

dentist. Sixteen of our Chapters operate Article 16 clinic networks, which serve individuals in upwards of 40 counties.

Two-thirds of The Arc New York's Article 16 clinics consistently run in deficit. Chapters are forced to consider closing their clinics altogether, or discontinuing crucial high-cost services, like psychiatry, in an effort to keep the clinics open. OPWDD has done a two-year review of Article 16 clinic programs statewide, and their findings align with our experience. Two-thirds of all New York's Article 16 clinics are running in deficit.

If a clinic discontinues a psychiatric program, what happens to the individuals in the care of that psychiatrist? With no one to manage their medication and psychiatric care, they likely end up in the Emergency Room in psychiatric crisis – a risk to themselves and possibly their community. These vital clinic programs keep people safe, provide consistent support, and avoid high-risk, high-cost emergency interventions by the health care sector.

The current funding model is not sustainable. OPWDD has proposed a strategy and recommendations for modifying the APG fee methodology, but we have yet to see adoption of those recommendations, or any adjustment in the current rate structure.

We need immediate funding support for Article 16 clinics. Without funding, clinics will be forced to close, and without clinics, thousands of people will be left in crisis.

Within this unsustainable landscape, we are charged with serving increasingly challenging populations: individuals with complex medical issues, mental health and behavioral health challenges – and at times forensic histories or criminal backgrounds.

The question of appropriate care and placement for individuals with a sex offender classification has recently ignited controversy in the media and the legislature.

This is not a simple issue. The law requires that services be provided to people with I/DD, regardless of a person's clinical or criminal background. Providing these individuals with an appropriate placement, supervision, and management plan under the care of trained staff best protects both the individual and the community from future offenses.

This is only one example of the complex supports our field provides. We are committed to taking on these challenges. We always have been. But to do so successfully, we need sufficient funding to train and retain skilled staff.

A recent state agreement with Centene and Fidelis Health care provided \$1.5 billion to support an increase in the hourly pay of healthcare workers, and Governor Cuomo is urging the Port Authority to increase the minimum wage for airport workers to \$19 an hour. These sectors deserve a fair wage, but our field is also in urgent need.

When I talk about our field I want you to remember that these are people, not products – people who cannot care for themselves, who cannot simply go to another doctor or another apartment, who need, in many instances, 24/7 support.

We appreciate the first two installments of bFair2DirectCare funding included in the last two state budgets, but they are only a start. Unless New York funds the last four phases of the living wage plan, our non-profits will continue to lose workers, and with them, the ability to provide appropriate care and support for New Yorkers with I/DD and their families.

Our field and the state are partners in the goal of effectively and compassionately providing services that meet these challenges and support a rich, full life for people with intellectual and developmental disabilities.

We will work with you to implement the transformation to managed care, and to thoughtfully identify opportunities for consolidation and efficiency wherever possible. However, we need to work together, and we need your support to succeed in those shared goals. The most critical support you can provide is appropriate transformation funding, and a living wage for our Direct Support staff.

Remember, Lauren, her friends, others with I/DD and their families are depending on you. The decisions you make will determine whether or not they will have fulfilling lives and be able to participate in their communities. Thank you



## COLA Deferral History from 2010-2018

Year	COLA Owed <i>According to Bureau of Labor Statistics</i>	Deferred or Paid	Comments
2010-2011	-2.1	0%	S6604B  Money was included to address a negative 1% COLA that would otherwise have carried over
2011-2012	1.2	0%	S2803E
2012-2013	3.6	0%	S6253E
2013-2014	1.4	0%	S2603E
2014-2015	2.0	0%	S6353E  Budget included a 2% increase for DSPs effective 1/1/15
2015-2016	2.0	0%	S2003C  Budget included a 2% increase for DSPs and clinical staff effective 4/1/15
2016-2017	.02	.02%	S6404D
2017-2018	.08	0%	S2003D
2018-2019	1.7	0%	S7503D
TOTAL	9.9%	.02%	
<i>2019-2020</i>	<i>2.9</i>	<i>TBD</i>	