



*A family-based organization
for people with intellectual
and developmental disabilities*

The Arc New York COVID-19 Impact Testimony

New York State Assembly Standing Committee on Mental Health

September 8, 2020

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Hearing on the Impact of COVID-19 on individuals with either a mental illness or an intellectual or developmental disability

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Chairwoman Gunther and members of the Assembly Committee on Mental Health, thank you for the opportunity to provide feedback on the impact of COVID-19 on individuals with intellectual and developmental disabilities (I/DD), their families, and providers of services across New York. You have asked if there has been an impact on access to services, and if there is a need for additional resources or policy changes as a result of the pandemic. The answer is a resounding “yes” to all three questions posed by this Committee.

During today’s testimony you will hear about resources funding cuts, and the need for innovation. However, the most essential impact of COVID-19 on the people and the families supported by The Arc New York is ultimately a human one. The field of human services is largely defined by our commitment to improving the overall quality of life for those we support. Unfortunately, the blows sustained by voluntary non-profit providers in recent years is now compounded by additional cuts, at a time when our spending on personal protective equipment, staffing, and safety measures is at an all-time high. As The Arc New York has expressed before, the stability of this critical network of supports and services for people with I/DD and their families is at risk and your acknowledgement, support, and partnership is needed now more than ever.

The impact of the COVID-19 pandemic on people with I/DD became the source of national news stories. Specifically, one group of specialists stated in a letter to the American Journal of Psychiatry that “people with [I/DD] were disproportionately isolated prior to the pandemic, and the intensification of that isolation stands only to weaken the community for all citizens.”

Here are just some of the headlines over the last several months:

“Developmental disabilities funds to be cut statewide”, Rockland/Westchester Journal News, 7/1/2020

“What a lost school year means for children with disabilities”, Washington Post, 8/4/2020

“Children with special needs face new challenges amid pandemic,” Today Show, 8/11/2020

“COVID-19 taking a toll on direct support professionals,” DisabilityScoop, 8/14/2020

“State’s canceled contract leads to job cuts, lawmakers push back,” Spectrum News, 8/19/2020

“N.Y.’s most vulnerable will suffer if the state cancels funding: disability advocates,” New York Daily News, 8/24/2020

“Covid-19 has disproportionately impacted those living with developmental disabilities,” CNN, 8/28/2020

The parents who founded our organization were among the earliest advocates for quality services and opportunities for people with I/DD. In the past 70 plus years The Arc New York has existed, we have witnessed – and at many times driven – massive transformation and progress in our field. Over those seven decades, New York state has developed a robust system of individualized, integrated services and supports that provides quality care and the opportunity for a rich, full life for 140,000 New Yorkers with I/DD.

We have weathered financial crises in the past, working with state partners and stakeholders to preserve these vital services and supports. However, the COVID-19 pandemic has presented an unprecedented challenge. While our costs have unexpectedly increased in order to protect our population and workers, state funding is continually being reduced and federal funding allocated to the state has been withheld and not made its way to providers. In addition, federal stimulus programs excluded non-profit providers of predominantly Medicaid services, who were not afforded the same opportunities as other organizations. Essentially, we are burning the candle at both ends without a clear path forward for how to maintain services.

We are at a crossroads and we must work together on solutions to serve this vulnerable population through this crisis and beyond. These are not optional services. They represent the core of New York’s constitutional and ethical obligation to ensure essential supports for the people and families we serve.

Initial Challenges: Health, Safety, and Costs

The Syracuse University study referenced by this Committee found that people with I/DD living in group homes across the state were more likely than other New Yorkers to contract COVID-19 and twice as likely succumb to the disease. It was, and continues to be, absolutely critical that we establish and adhere to stringent safety parameters with urgency to protect New Yorkers with I/DD and our dedicated workforce. However, support from the state was

virtually non-existent. There were no additional resources allocated for the procurement of Personal Protective Equipment (PPE), no offer for access to state or local contracts for PPE, no assistance in complying with executive orders and Department of Health guidance. We are frontline providers of essential health services, and yet the state was ill-equipped to provide us even a basic level of support. The Arc New York found itself scrambling to create contacts and purchase PPE from vendors whose costs were rising with demand. We purchased gloves, gowns, face shields, hair covers, thermometers, and masks from every possible source to ensure that our Chapters and their employees had the necessary supplies to keep them safe and in compliance with health regulations.

Our Direct Support Professionals (DSPs) have been unsung heroes throughout this pandemic. As you know, these caring people support individuals in their homes. Working in COVID-positive locations was an everyday reality for them. They donned PPE and put themselves at risk to ensure the people we serve remained supported and connected. Many of them took on this risk above their own personal safety and that of their families, often while home schooling their own children. The Arc New York owes an incredible debt of gratitude for the sacrifice our staff made and continues to make every day to sustain enriching and safe programming under incredible circumstances.

The instability caused by COVID-19 on the direct support workforce cannot be underestimated. A recent study cited in one of the above news stories found that almost 50% of staff know someone who has left the profession due to the pandemic. With our current vacancy rates, this is an outcome we cannot afford. Once again, we implore the State of New York to recognize the direct support staff for the important role they play and to provide adequate funding to enable voluntary providers to pay these dedicated and skilled workers what they deserve.

In a survey conducted by the New York Disability Advocates (NYDA), for the period of March 1, 2020 through May 31, 2020, not-for-profit providers statewide incurred \$74 million in additional COVID-19 payroll costs to ensure staffing needs were met, \$16 million to procure personal protective equipment (PPE) and close to \$10 million in other expenses directly related to the pandemic. These added expenses, combined with lost program revenue in excess of \$81 million, have had a devastating impact on the system. Since December 2019, the number of providers with less than 30 days of cash on hand has increased by 40%.

While the State received a 6.2% increase in FMAP, of which OPWDD received an allocation for COVID-19 related expenses, none of that funding has been or is expected to be made available to the voluntary not-for-profit providers that support 85% of the individuals with I/DD in New York State.

Fiscal Challenges: A Threat to Current and Future Access

In the face of the state's challenging fiscal outlook, we need to approach even short-term policies with long-term vision, however we are currently facing short-term fiscal solutions that would have a devastating and lasting impact on services for New Yorker's with I/DD.

Discontinuation of Retainer Days

On July 1, 2020 the Center for Medicare and Medicaid Services (CMS) suddenly announced that retainer day funding would be capped at 3 consecutive 30-day periods. Our Chapters had been receiving retainer day funding since March 18, 2020, which was essential in providing the funds necessary to retain critical staff, such as DSPs, during the initial closure of day programs. In New York, the 90-day retainer limit was met as of July 21, 2020.

Although the OPWDD announcement and guidelines allowing day programs to reopen was timely given the discontinuation of retainer day funding, the return to full capacity in such a short timeframe was unrealistic. We faced continued safety concerns, the development of new protocols and procedures, and, understandably, the hesitance of individuals and families to return to day programs. Provider Associations led by The Arc New York developed a proposal, which allowed some flexibility through OPWDD, however that flexibility expires on October 14 of this year. This stopgap solution was helpful in the interim, but it does not permit providers to create sustainable service delivery models moving forward. We cannot depend on short-term solutions to stabilize a system in crisis and maintain quality access to services into the future.

Rate Reductions

The New York State Department of Health also proposed cuts in reimbursement to voluntary providers serving individuals with I/DD in group homes and other residential programs for those who are medically frail. The cut, planned to go into effect on October 1, 2020, will significantly impact families and the providers who serve their loved ones. These cuts will strip approximately \$200 million annually from the system and result in a reduction in reimbursement of much as 7.5% for certain residential programs with significant vacancies, including vacancies due to deaths from COVID-19. This action was taken without any consultation or discussion with stakeholders.

These cuts accomplish savings in three ways:

- Eliminating funding to voluntary providers that supports operating costs while vacancies are being filled (the "occupancy adjustment")
- Reducing by 50% funding to cover operating costs when an individual is temporarily out of their home due to hospitalization ("retainer day" funds)
- Reducing and capping funding to an individual's provider when their family takes them home to visit or for a holiday ("therapeutic leave days")

These proposed cuts fail to consider that the “beds” those with I/DD occupy are not temporary placements, like a hospital or a rehabilitation center. These are the homes of the people we support. Homes they may come and go from in crisis, or for connection. Homes they have a right to return to. These cuts would jeopardize that basic security. Just as our own expenses do not go away when we are on vacation or in the hospital, the costs to a provider do not vanish when an individual they support is away from home. Imagine a family who is burdened with the knowledge that spending time with their loved one could cause financial harm and instability to the place they call home. Families should be encouraged and supported in staying connected with their loved ones throughout their life. Providers should not suffer a financial penalty for family connection, and families should not be discouraged from such visitation.

The costs for delivering direct care – 80% of which is the salaries paid to direct care staff, clinical staff and residence supervisors – are fixed and can’t be reduced simply because an individual supported is out of the house. Our dedicated staff provides care around the clock for everyone in a home. If one person is in the hospital, providers cannot place a staff member on unpaid leave until that hospital stay is over.

After years of underfunding by the New York state, voluntary providers have been cut yet again. This action will no doubt cause a decrease in the number of residential openings in the state at a time when there is a waiting list for many families. New York has a constitutional obligation to care for its most vulnerable citizens. Our family members are not just numbers on a spreadsheet, their homes should be protected, safe, and available for them regardless of whether they visit family or need medical assistance.

20% Withhold

In addition to the challenges outlined above, two weeks ago OPWDD announced that the Division of the Budget is requiring a 20% withhold on all current quarterly payments of non-Medicaid state aid funding. This source of funding provides critical supports such as rent subsidies to individuals living in their own apartment, family support services to families caring for a loved one at home, room and board subsidies to providers, support for aging out children in private residential schools, and other supports. All told, non-Medicaid state aid funding equates to approximately \$300 million annually. The 20% withhold represents approximately \$15 million for this quarter. Fortunately, OPWDD was successful in getting an exemption on state aid payments for rental subsidies to individuals living in their own apartments, thereby averting an immediate crisis.

Improved Access to Services: Telehealth and Teleservices

The COVID-19 crisis expanded use of telehealth services to meet the critical medical needs of people across the state. For the first time, many residents received swift care at a time when meeting in person with medical professionals was difficult or entirely forbidden.

Access to care across multiple medical disciplines finally became a possibility, whereas previous regulatory and statutory barriers made it logistically challenging or impossible to offer services in such a way. Healthcare delivery in this manner has been sought by I/DD service providers as an option for flexible quality care for individuals. We have witnessed efficacy and savings with this technology and support solidifying this with other flexibilities into the future.

The Center for Medicare and Medicaid Services (CMS) has indicated a willingness to accept innovations to service delivery, including day and community habilitation, through remote services. However, it will be incumbent upon New York to propose and support changes to its federal waivers. As the entire world came online to live day by day, forge forward, and accomplish life goals, there is no reason why people with I/DD should not be afforded the same benefits.

The Arc New York seeks to make permanent the expansion of Telehealth and Teleservices found in Governor Cuomo's Executive Order 202 and the March 31, 2020 Department of Health Guidance document. We support A10715 (Gunther)/S8688 (Harckham) and A10723 (Rosenthal)/S8785 (Harckham), which seek to bill services at standard in-person rates.

Additionally, we will continue to seek service model innovations to include teleservices on par with current programs and rate conventions. Billing codes must be clear and embrace new methods for achieving an individual's life plan. Rates for services should be based on outcomes, rather than mode of delivery. As the Empire State, flexibility and creativity are ours to propose. We have historically served as a model to other states. We must protect that legacy while we seek continuous improvement despite our collective challenges.

Innovation to Preserve our Future

At the core, access to services through this pandemic and beyond is anchored to the sustainability of voluntary providers like The Arc New York and our Chapters. Additional state resources are desperately needed as we face a potential second wave of COVID-19. We will continue to propose policies and procedures that both improve efficiency and service quality. While we are open to changes, any transformation we undertake must sustain or strengthen the system of supports and services, not erode it. We hope the Governor, OPWDD and the legislature believe the same.

Technology has the potential to be an important tool in delivering quality services while protecting our population, and our workforce. During the pandemic, we have used technology in ways we might not have imagined even ten years ago. We have modified policies to allow online voting and decision making, and transformed the way we work. It is time to take a hard look at our current service model and view online or modified service delivery options as an opportunity. It is up to New York state to be the leader once again. The Arc New York and our partners are willing and able to work together in order to preserve the state's promise and obligation to individuals with I/DD. We have utilized a 20th century model for too long. We must now bring ingenuity to the forefront, cast aside fears, and strive for excellence and innovation in all we do.

Thank you again for the opportunity to reflect on these challenges, offer insight, and propose ways to move forward in meeting our obligations to the people we serve.