



The Arc[®]

New York

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

Executive Director Mark van Voorst's Testimony

*Joint Legislative Hearing of Senate Finance and Assembly
Ways and Means Committees on FY 2018-19 State Budget*

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Achieve with us.

Overview

The Arc New York, a family-led organization founded in 1949, is the largest nonprofit organization in New York State supporting people with intellectual and developmental disabilities, including Down syndrome, autism, and cerebral palsy. With 52 Chapters across the state, The Arc New York supports 60,000 individuals, employs 30,000 people, and has more than 100,000 members. We are the New York State Chapter of The Arc, and our mission is to advocate for and provide services to people with developmental and other disabilities in every manner possible.

It is becoming increasingly difficult for The Arc New York to fulfill its mission due to the worsening workforce crisis, insufficient residential development, and the systemic flaws of rate rationalization. Additionally, we do not have sufficient financial support to effectively transform to care coordination and ultimately managed care. Finally, the budget does not include any additional funding for preschool programs despite the fact that our preschool services system is on the verge of collapse. We project that without growth factors and necessary changes in the tuition methodology, six or more of The Arc New York's remaining 19 comprehensive 4410 preschool programs will be forced to close.

Worsening Workforce Crisis

The latest data released from our #bFair2DirectCare coalition shows that vacancy and turnover rates are getting worse. In 2017, 14%, or one in seven, of all Direct Support Professional (DSP) positions were vacant. This is a 30% increase since 2016, and 80% increase since 2014. The staff turnover rate also increased in 2017 to 27%, an 8% increase since 2016, and 42% increase since 2014. One in three DSPs leave the job after less than six months.

Without DSPs, we cannot support the thousands of New Yorkers with developmental disabilities and their families who rely on us. DSPs provide 24/7 support, teach essential living skills, supervise daily activities, assist with personal hygiene, meal preparation, manage physical and behavioral health, support the delivery of needed medical services in both routine and crisis circumstances, and provide friendship and emotional support. DSPs undergo hours of intensive training in communications, medication administration, behavior management, fire safety, CPR, first aid, and incident reporting.

While we continue to be grateful for the initial funding provided to begin to provide DSPs a living wage, it is critical that additional funding be included in the state budget to ensure the continuation of critical services for those with developmental disabilities.

Insufficient Residential Development

Many people with developmental disabilities and their families worry about the future, and whether or not they or their loved one will ever have a home of their own. This anxiety becomes more acute as caregivers age and in-home care inevitably becomes more difficult. The availability of residential opportunities is a longstanding issue, and is a growing problem for a number of reasons.

First, while OPWDD has provided some information to illustrate the scope of the problem, such as the number of people on the waiting list, there continues to be a pervasive concern about the accuracy of this data. This lack of confidence in the data undermines confidence in the broader effort to resolve the residential issue. We need to address this so we can begin to fix the system, and regain the trust of families and their loved ones we support.

Second, due to OPWDD's limited resources and staff attrition, there is a concern that the agency does not have the capacity to utilize existing vacancies or develop new residential opportunities in a timely manner. Frankly, if OPWDD were appropriated all the capital and operating funding it could conceivably need, those funds could not fix the situation without sufficient administrative and operational staff.

Compounding these concerns is the worsening workforce crisis because smaller, person-centered residential opportunities require more, not less staff; and existing staff vacancies have forced the discontinuation, rather than expansion, of existing residential space.

Flaws of Rate Rationalization

Four years ago, CMS required New York State to change the way developmental disability providers were funded, and mandated the use of cost-based rates. This “rate rationalization” has eliminated the ability of providers to offset losses in one program by maximizing efficiency savings in other programs. As a result, we continue to struggle to operate essential, yet underfunded programs including clinic services such as psychiatry, dental, neurology, and others.

Rate rationalization also fails to account for both routine increases in operating costs (i.e., rent, utilities, insurance, etc.), and unanticipated revenue loss due to snow days, flu epidemics, and other unbillable vacancies. In addition, many program rates are calculated with the assumption that providers will perform at 100% capacity, and when this inevitably does not happen due to factors often beyond the provider’s control, the program operates with reduced revenue.

Rate rationalization has also diminished reimbursable direct support hours just when the challenges to providing adequate direct support staffing have become insurmountable for many providers. This has created a threat to safety, the quality of care, and providers’ ability to integrate individuals into the community.

Insufficient Transformation Funding

The developmental disabilities service system is being asked to transform itself without sufficient financial support. While the Executive Budget includes \$78 million to convert the Medicaid Service Coordination system to a Care Coordination system as a first step towards managed care, the budget does not provide any startup funding to help developmental disability service providers build their infrastructure or comply with extensive federal Home and Community Based Setting requirements in preparation for the shift to managed care. We are looking for a comparable investment to what the health care sector received to prepare for this significant transformation, including funds to build a uniform information technology infrastructure.

Additionally, we are looking for assistance to expand our use of telemedicine. Telemedicine has enormous untapped potential to improve care; save resources; and relieve stress on direct support and clinical staff enabling them to work more efficiently. One large developmental disability provider reported an 86% decrease in expensive emergency room visits through the use of telemedicine. Funding is necessary to purchase equipment needed to deliver telemedicine and OPWDD must promulgate regulations to enable providers to bill Medicaid for telemedicine services. Telemedicine is a revolutionary opportunity to improve the delivery of health care services.

Preschool Services System on Verge of Collapse

Chapter 4410 preschool programs provide critical services to children with disabilities ages 3-5 and their families. Programs have received two 2% increases over the last seven years. In addition, rate increases are subject to an annual State Education Department reconciliation process that further reduces funding each year.

The Governor’s Executive Budget does not include additional funding for preschool programs despite the fact that the system of preschool services is on the verge of collapse. Preschools that serve children with developmental disabilities started closing more rapidly in 2016, and the pace of closures will accelerate without intervention. We project that without growth factors and necessary changes in the tuition methodology, six or more of The Arc New York’s remaining 19 comprehensive 4410 preschool programs will be forced to close.

Due to the various challenges illustrated above, The Arc New York requests the following:

Budget Requests

- \$18.25 million in the FY 19 budget to begin phase 3 of bFair2DirectCare campaign aimed at providing a living wage to Direct Support Professionals by 2020. Along with phases 4 (effective 4/1/19) and 5 (effective 1/1/20) of the campaign, the total annualized cost to complete the campaign would be \$219 million.
- \$25 million to fund additional residential placements for 500 people living at home with aging caregivers, and establish a transparent, uniform statewide process for allocating residential placements.
- Enable developmental disability providers to establish a statewide telemedicine capability by adding language (1) requiring regulations necessary to allow them to bill Medicaid and (2) granting them access to a developmental disability infrastructure and payment fund to purchase equipment and enhance payments to clinicians and/or telemedicine providers. The fund would be paid for with savings from reduced emergency room admissions and fewer trips to see medical professionals.
- \$14 million for teacher recruitment and retention in 4410 and 853 schools.
- A 4% tuition increase for 4410 and 853 schools which reflects the anticipated state aid increase for general education in the final FY 19 Budget.
- Provide a 4% increase for Early Intervention providers.
- Fund a Medicaid trend factor based on the Bureau of Labor Statistics Medical Consumer Price Index to provide parity with state-run developmental disability services and much needed funding to pay for the cost of inflation. BLS has not yet published its Medical Consumer Price Index for FFY 18.
- Eliminate the penalty rate rationalization imposes on efficient providers by confiscating savings. Instead, allow provider to reinvest savings into other critical, but underfunded programs.
- Support proposed Article VII language making permanent the authority of social workers and non-licensed psychologists to engage in activities otherwise performed by licensed psychologists. The current authorization is slated to sunset in SFY 2018-2019.