



*Coalition Of Provider Associations*



The Coalition of Provider Associations, or COPA, consists of five associations – the Alliance of Long Island Agencies, Inc. (ALIA), Cerebral Palsy Associations of New York State, Inc. (CP of NYS), the Developmental Disabilities Alliance of Western New York (DDAWNY), the InterAgency Council of Developmental Disabilities Agencies, Inc. (IAC), and the New York Association of Emerging and Multicultural Providers (NYAEMP). Together we offer comments and recommendations on the Mental Hygiene section of the 2019-2020 Executive Budget proposal.

**OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES**

- A Living Wage for Direct Support Professionals
- The Human Services COLA
- Residential Development
- Funding for Individuals with Complex Needs
- Financial Stability for Clinics Serving People with I/DD

The Office for People With Developmental Disabilities (OPWDD) funds services and supports for people with intellectual and developmental disabilities (I/DD) and their families throughout their lifespans. Residential, day, employment, clinical and other supports enable New Yorkers with I/DD and their families to live lives that others take for granted. Currently, however, our nationally recognized service system is in trouble! Years of deferred COLA/Medicaid Trends prevent nonprofit providers from keeping up with the rising cost of providing services and cuts and rate changes penalize providers serving the highest need individuals. A growing population whose needs are intensifying, with aging parents and caregivers who need more help just to maintain status quo, combined with a Direct Support Professional staff recruitment and retention crisis threatens the very existence of services. These factors, coupled with our ongoing system transformation to managed care, has resulted in financially stressed providers, increasingly unable to sustain operations.

✓ **CONTINUE TO INVEST IN A LIVING WAGE FOR CRITICAL WORKERS**

Direct Support Professionals (DSPs) are the approximately 100,000 people (full time and part time) who deliver the services that individuals with developmental disabilities and their families depend on, 24 hours each day, seven days a week. These highly trained staff members perform mentally, emotionally and physically demanding work, requiring sophisticated judgment and decision making. In many cases, the health and wellbeing of the people they serve rests entirely on their shoulders. These are far more than minimum wage jobs, yet years of grossly inadequate funding have led to wages that have lagged behind where they should be considering the importance of the work.



The Office for People With Developmental Disabilities (OPWDD) Aid to Localities budget includes \$47.4 million to continue to provide funding to implement the new minimum wage, but nothing to continue the phase in of a living wage for our lowest paid staff. We are grateful to the Governor and Legislature for recognizing the need to address this issue and including funding for the first two phases in previous budgets. We now look forward to New York State's continuing support to enable the future steps required to reach our living wage goal. Our recently updated statewide survey of providers shows that for 2018, average vacancy rates have remained steady at 14.3% and the average turnover rate has also remained steady at 26.4%. Overtime hours have increased, however, from 10 million to 12 million hours, at a cost of approximately \$88 million. We assume that the first two installments toward a living wage kept our vacancy and turnover rates from increasing and hypothesize that the increase in overtime hours is due to increased need for services without an increase in available staffing. As you can imagine, staff who work more hours are increasingly burdened, tired and stressed. Not an ideal situation to say the least, and one that can easily lead to dangerous mistakes.

As background, unlike hospitals and other healthcare providers, those who support individuals with I/DD are almost exclusively funded through Medicaid with no alternative source of funding to increase wages. We cannot raise our prices or otherwise substantially increase our revenue. If we can't attract and retain qualified workers, we are forced to accept less qualified applicants and/or reduce the amount of support we provide for each person and/or cut services. Labor is by far the largest component of our budgets. Nearly 80% of personnel funding goes directly to compensation for front-line staff who provide direct supports. Unlike other sectors, where automation and use of technology may offer alternatives, the supports we provide require talented human beings.

The living wage we seek to achieve (\$17.72 downstate and \$15.54 for the rest of the State) over six years, is the least we can do for dedicated professionals who make life worth living for New Yorkers with I/DD and their families. COPA has joined every association in the State representing individuals with I/DD and their families, including The Arc New York, The New York Alliance for Inclusion and Innovation, DSPANYS (the Direct Support Professional Alliance of NYS), SANYS (the Self Advocates Association of NYS), and the parent group SWAN (the State Wide Advocacy Network), to form the #bFair2DirectCare Coalition.

Without an adequate supply of qualified staff, incidents which endanger the welfare of the people in our care will increase, those staff who stay will experience "burn-out" due to the burden of increasing overtime hours worked and staff, families and, most importantly, the people with I/DD who depend on us will suffer. There is no safety net beyond not-for-profit providers. Of the more than 138,000 New Yorkers with I/DD supported by OPWDD, most are supported by the 100,000 direct support professionals and other staff in our nonprofit, community-based organizations. In short, the staffing crisis is not improving yet, and we urge you to continue your support for #bFair2DirectCare in the FY 2020 budget.

- **Recommendation:** Provide the third (4/1/19) and fourth (1/1/20) installments (in our six installment plan) in this budget to continue the move to a living wage for Direct Support Professionals.

**Cost: \$75 million (State share)**

✓ **PROVIDE A COLA/MEDICAID TREND IN THIS AND FUTURE BUDGETS**



The lack of COLA/Trends for many years has prevented nonprofit providers from keeping up with rising costs, paying competitive salaries, and has created the dire staffing emergency that the #bFair2DirectCare campaign seeks to address. This year, COPA is teaming up with the STRONG NONPROFITS FOR A BETTER NEW YORK campaign to help make it known that the Human Services COLA must not be deferred this year! Prior to 2011, Medicaid funded OPWDD supports and services received yearly

increases to cover the rising costs of providing services, called “Medicaid Trends,” similar to a COLA for non-Medicaid expenses. In 2010, a COLA/Medicaid Trend of 2.08% was given to both state and nonprofit operated programs. Since that time, with the exception of 0.2% given in 2017, nonprofit OPWDD providers have been denied any COLA/Trend to support agency operations. Federal and State laws require that all payments to providers be based upon the reasonable cost of services. Reasonable costs take into account both direct and indirect costs, including personnel, administrative, employee pension plans, rising health and liability insurance costs, workers comp and normal standby costs (related to unoccupied beds). We strongly advocate for the statutory COLA to be included in this and future budgets. Only STRONG NONPROFITS provide quality services!

- **Recommendation:** Include the 2.9% Human Services COLA/Medicaid Trend in the FY 2020 budget  
**Cost: \$140 million (State share)**

✓ **ADEQUATELY FUND SUPPORTS FOR INDIVIDUALS WITH COMPLEX NEEDS**

For those among us who have complex medical or behavioral needs, there has always been a shortage of services and supports available. This shortage has been exacerbated in recent years with reimbursement methodology changes removing nonprofit providers’ flexibility to respond to emerging needs for increased supports and staffing for this group. As an example, special education students with complex needs, who should expect to transition into OPWDD adult services as they age out of school, are often left waiting at home with no supports or services. We have seen time and again that Medicaid reimbursement rates for OPWDD services, especially through DOH programs that include the typical population, fail to support the higher level of supports needed for those with complex medical and behavioral needs. Some of those in our programs have had complex needs from birth but there also is a large contingent whose needs have increased due to aging, a traumatic incident or other life-event. Planning and funding are required so that everyone, regardless of severity of disability, can participate as fully as possible in their communities and not languish at home, isolated, waiting for us to step up to the challenge. Providers must be able to quickly and flexibly respond to the emerging needs of the people they support.

- **Recommendation:** Include funds to support people with complex needs currently receiving services, for whom current rates do not cover the cost of the person centered supports they require.  
**Cost: \$10 million**

✓ **PROVIDE ADEQUATE FUNDING FOR THE DEVELOPMENT OF OUT OF HOME RESIDENTIAL OPPORTUNITIES**

COPA is acutely aware of the challenges facing New York State in allocating resources and balancing the needs and priorities of competing interests. The field of I/DD has done more than its share of belt tightening as described above. As a result, thousands of New Yorkers with I/DD are being denied supports or receiving only limited supports that do not fully meet their needs.

After so many years of flat funding and reductions, even the most optimistic allocation is inadequate to meet the needs of the thousands waiting for community-based services. According to OPWDD's 2016 report on the Residential Request List, among the thousands of people on the wait list: 46% live with caregivers over the age of 60; 53% have only one caregiver at home; and 48% need help with almost all of their daily living activities. While we appreciate the inclusion of an additional \$120 million (all shares fully annualized) in the Governor's proposal, the need for services, including day, at home support, out of home residential and other services, far surpasses this proposed allocation, particularly for those who can no longer live safely at home with their families. Also, based on information from mid-year spending updates, while \$120 million had been approved in the last few budgets, it was not entirely spent. Therefore, we must note that it is critical that any barriers to spending the entire \$120 million allocated this fiscal year be removed.

We also support the inclusion of another \$15 million in the Executive's proposal to expand affordable housing. Quality, affordable, accessible housing with the services and supports necessary to permit individuals with disabilities to become part of the community is essential. This funding is, however, spoken for even prior to the dollars becoming available and OPWDD providers have had difficulties accessing the larger affordable housing pool under the Division of Housing & Community Renewal (DHCR).

- **Recommendation:** Provide additional funds for the capital costs of developing affordable housing opportunities for people with developmental disabilities  
**Cost: \$15 million**
  
- **Recommendation:** Set aside \$20 million of the \$120 million in development funds for residential opportunities for those who can no longer safely live at home with families  
**Cost: No additional cost**

✓ **PROVIDE FINANCIAL STABILITY FOR CLINICS THAT SERVE PEOPLE WITH DEVELOPMENTAL DISABILITIES**

For almost forty years, New York State has counted on clinics supporting patients with significant disabilities to fill an essential gap in the service delivery system, one which otherwise would lead to expensive and unnecessary services delivered in emergency room and acute care settings. Over time, voluntary agencies supporting people with disabilities have stepped up to ensure their access to health services across the State through an array of Article 16, Article 28 and Article 31 clinics. These clinics have evolved to become true specialty service providers, serving patients with the highest needs and often at a financial loss. With rate rationalization removing any surpluses to help providers to subsidize these clinics, the insufficient funding of clinical disability services has been glaringly exposed. The annual 20% loss on operations of our clinics no longer can be sustained and Boards statewide are facing tough decisions about the future of a variety of disability services.

To date, when Boards choose to close disability clinics, patients, in most instances, have no good option. In the absence of primary care, dental patients show up in the ER and operatory procedures are required for issues that easily could have been avoided with more timely primary care. Clinic visits are replaced with ER visits for untreated conditions that may not require, but almost always generate MRI and other expensive diagnostic tests because the patient is unable to communicate and has no previous relationship with the ER physicians. This would lead us in exactly the opposite direction from the one New York State has been moving toward.

In March of 2018, NYS DOH and OPWDD jointly established the *Clinic/APG Base Rates Workgroup* to address the concerns that Article 16 and 28 clinics operated by OPWDD nonprofit agencies would cease to exist due to fiscal difficulties and operating shortfalls. In order to prevent New York State from incurring unnecessary Medicaid costs, we recommend the State invest in these specialty clinics supporting patients with I/DD and recognize them as an essential part of the service delivery network.

Following are a few of the DOH/OPWDD *Clinic/APG Base Rates Workgroup* recommendations:

- **Recommendation:** Fund Article 16 deficits to cover the cost of providing services.  
**Cost: \$5 million and will produce savings from prevented/reduced ER visits and acute care utilization**
  
- **Recommendation:** Repeal MRT 26 rate penalties.  
**Cost: \$2.4 million and will produce savings from prevented/reduced ER visits and acute care utilization**

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