



*Coalition Of Provider Associations*

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**TESTIMONY SUBMITTED TO THE  
NEW YORK STATE LEGISLATURE**

**Joint Hearing of the  
Senate Finance and Assembly Ways and Means Committees**

**2019-2020 Executive Budget  
Mental Hygiene**

**Presented by**

Barbara Crosier  
Vice President, Government Relations  
Cerebral Palsy Associations of NYS

**&**

Winifred Schiff  
Associate Executive Director for Legislative Affairs  
The InterAgency Council of Developmental Disabilities Agencies

**For the Coalition of Provider Associations**

**February 7, 2019**

***Representing More Than 250 Providers in New York State***

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Good afternoon Committee Chairs Krueger, Weinstein, Carlucci, Gunther and members of the Senate Finance Committee, Assembly Ways and Means Committee, and the Mental Health and Developmental Disabilities Committees. Thank you for your ongoing support of people with Intellectual and Developmental Disabilities (I/DD) and for the opportunity to speak with you today regarding Governor Cuomo's 2019-20 budget proposal.

I am Wini Schiff of the InterAgency Council of Developmental Disabilities Agencies (IAC) joined by Barbara Crosier from Cerebral Palsy Associations of New York State (CP of NYS). JR Drexelius from the Developmental Disabilities Alliance of Western NY (DDAWNY), who was unable to join us today, is with us in spirit. We are here today on behalf of the Coalition of Provider Associations, or COPA.

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) – which came together because people with disabilities, their families, and the organizations that support them recognized the need to unify in our efforts to preserve and enhance services for New Yorkers with I/DD and their families. COPA represents over 250 not-for-profit agencies across New York State which provide supports and services to over 100,000 New Yorkers with I/DD and employ more than 120,000 dedicated professionals with combined annual operating budgets of nearly \$5.2 billion.

On behalf of COPA, we are grateful to the Legislature for your prior commitment to the #bFair2DirectCare initiative and our workforce. We seek your continued support and investment in a living wage for Direct Support Professionals and to preserve and strengthen the system of supports and services for individuals with I/DD that we have proudly built together. We must work in concert to uphold the promises we have made to those who depend on us every day.

## **OPWDD BUDGET BACKGROUND**

The Office for People With Developmental Disabilities (OPWDD) Aid to Localities (ATL) budget has remained basically flat over the past seven years. In only three of the last seven years, the adopted budget contained increases to ATL spending. With mid-year reductions, however, the actual spending has consistently been less than the budgets would indicate. For example, in fiscal year (FY) 2018, ATL spending on OPWDD programs was \$93 million less than FY 2017. For FY 2020, proposed spending is \$97 million higher, but due to these mid-year adjustments, even with this addition there has been a cumulative reduction in spending over the past 8 years of \$44 million.

In addition, while actual spending has been reduced each year, there has been virtually no Medicaid Trend for inflation since 2010. While we were more than appreciative of the increases for certain staff salaries in 2015, 2018 and 2019, the budget has included zero dollars for inflation to pay for the rising cost of workers comp, liability insurance, employee health care costs (which have risen by nearly double digits annually), rent and the myriad other fixed costs involved in providing services. Dating as far back as 1993, a Medicaid Trend was provided every year. These increases enabled providers to keep salaries competitive and maintain fiscal health while providing needed

services. The absence of these trends has led to the system's current lack of stability, with many providers financial status falling well below acceptable norms for liquidity and other performance ratios. The poor fiscal health of many providers comes at a time when investments in systems needed for the planned transition to managed care are absolutely necessary if these providers are to continue to fulfill the non-profit community's role as delivery system providers. Not only, are disability providers as a whole ill-positioned to transition to managed care, they have lost considerable ground in the fierce competition for workers who will help them fulfill their missions.

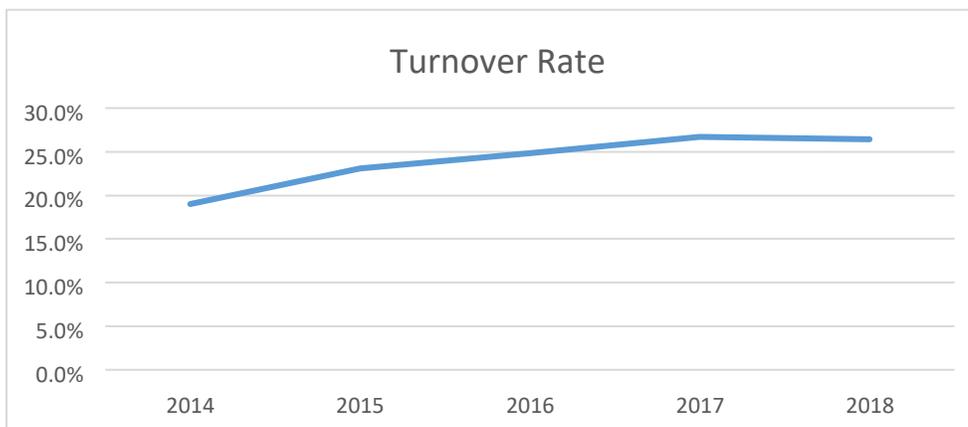
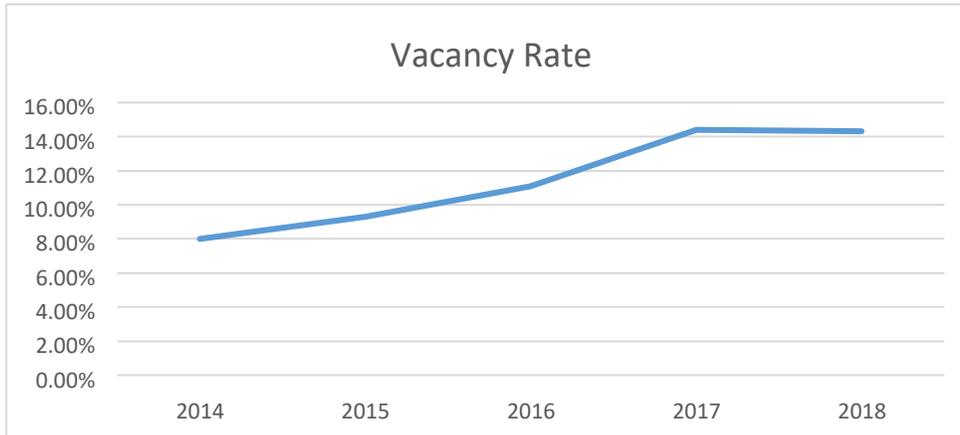
At the same time the cost of doing business has not been recognized, our system has undergone a rate rationalization process that has removed any opportunity for surpluses that could offset increased costs for utilities, insurance, etc., or sustain other underfunded services like clinics, Early Intervention (EI) and 4410 pre-school programs and other services for people with the most significant needs. Clinics have lost almost 20% on operations but were able to continue to provide life-sustaining services through these surpluses. The current "no margin" environment, however, is forcing the closure of programs that cannot sustain themselves, reducing access to services and penalizing providers supporting higher cost individuals.

Individuals may have received authorization for services, but due to the staff shortage crisis, in conjunction with the enhanced staffing that some high needs individuals require (for which there is inadequate reimbursement), actual services are unavailable. We look to the Legislature to work with us and the funding agencies to review the impact of the reimbursement policies of the State Education Department (SED), OPWDD and the Department of Health (DOH) as they impact the whole of services available to support people with I/DD and their families.

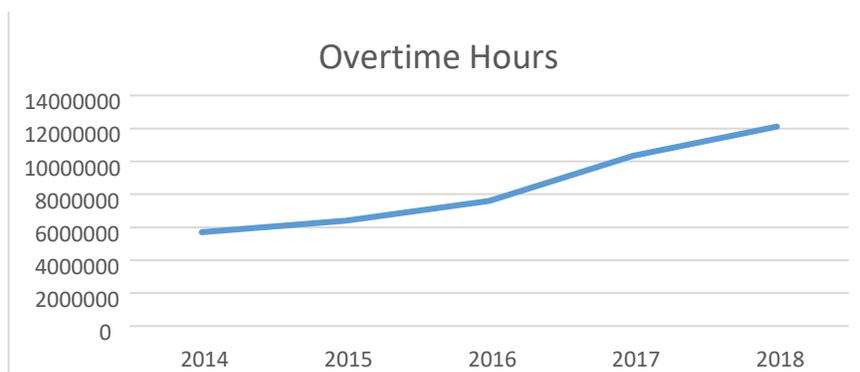
To summarize, providers of supports and services for individuals with I/DD are facing: the continuing rising cost of providing services; reimbursement policies which penalize providers serving the highest need individuals, a population whose needs are growing in intensity; aging parents and caregivers who need more help with their loved ones just to maintain status quo; a staff recruitment and retention crisis that threatens the very existence of services; total system transformation into a managed care environment; and all of this with reduced funding.

### **#bFair2DirectCare**

The OPWDD Aid to Localities budget includes \$47 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 including the first two phases of the six-year strategy to reach a living wage in the 2018 enacted budget and implore you to continue to take steps to reach this goal by adding the next two phases in the final 2020 State budget. Our recently updated survey of providers across the State shows that for 2018, vacancy rates have remained steady at 14.3% and the turnover rate has also remained steady at 26.4%.



Overtime hours have increased from 10 million to 12 million with a cost of approximately \$88 million. We are hopeful that the first two steps 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 to meet the needs of New Yorkers in need of support 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, with approximately 75% of personnel funding going 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 members depend on increased wages for low paid workers – especially those providing direct supports to individuals with I/DD. We have joined every association in the State representing individuals with I/DD and their families including DSPANYS (the Direct Support Professional Alliance of NYS), SANYS (the Self Advocates Association of NYS) and the parent group SWAN (the StateWide Advocacy Network) to form the #bFair2DirectCare Coalition. As previously stated, we commend both the Governor and Legislature for supporting the initial steps in this endeavor and look forward to continuing to work together to realize the goal of a new living wage for our dedicated professionals in the near future.

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 130,000 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 by adding \$75 million beginning 4-1-19 to move our low wage workers one step closer to a living wage.

## **COLA**

The lack of COLA/Trends for many years has prevented non-profit 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 non-profit operated programs. Since that time, with the exception of 0.2% given in 2017, non-profit 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. Not only have disability services providers not received increases for costs related to fuel, staffing, insurance, and other business expenses, we have not received the needed regulatory relief for the overwhelming and outdated paperwork and system approval processes that are continuously being added due to changes in interpretation of longstanding and outdated statutes, the Justice Center, new regulations which are retroactively implemented, cumbersome new billing requirements, etc., all which add to the regulatory burden and costs without any additional funding. Expenses related to staff background checks, the OPWDD Front Door process, outdated regulations and the Justice Center have grown steadily at the same time that our funding had been cut. Only **STRONG NONPROFITS** provide quality services, and we ask that you recognize and support Human Services providers across sectors by adding \$140 million to the enacted 2020 State budget.

## **DEVELOPMENT**

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. 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 proposal, particularly for those who can no longer live safely with their families.

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).

The Residential Request List (RRL) and Certified Residential Opportunity (CRO) lists are a good attempt at gathering information on need and planning for future residential needs; unfortunately, families and professionals are often unfamiliar with the process for getting on the lists – there is a crucial need for training and information dissemination. Federal rules regarding Home and Community Based Settings Standards and size of the homes are additional complications but federal mandates to honor choice dictate that requests for not sharing bedrooms, living with compatible roommates, etc., should be granted. We need eligibility determinations to be streamlined and creative, cross-agency funding opportunities to be explored.

Additional supports and services must be made available for those with complex medical and behavioral challenges, especially in light of the aging I/DD population for whom the current system is not responsive. Individual Support Services (ISS) funding, which covers the rent for

those able to live more independently in non-certified residential settings, is another option which could serve to create additional vacancies in existing certified housing situations, but the rent subsidy caps are too low to reflect market values in many areas of the state. In addition, it often takes three months to a year for OPWDD to reimburse providers which are forced to cover the rent for that period of time. While some larger organizations have found ways to subsidize the program, this delay severely limits its success.

We seek your support for funding the development of appropriate opportunities for individuals who need them and when they need them.

### **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 the reimbursement methodology changes leading to the inability of nonprofit providers to design rich enough supports and staffing to meet the requirements of those with complex needs. As an example, special education students with complex needs, who should expect to transition into OPWDD adult services as they age out of special education services, are often left waiting at home with no supports or services. We have seen time and again that Medicaid formulae promulgated for OPWDD services, and in a more pronounced way through DOH programs that include the typical population, fail to support the level of supports and/or the flexibility necessary to design person-centered services for those with complex medical and behavioral needs. Some of those we support have had complex needs from birth, but there also is a large contingent that, due to aging, a traumatic incident, or other life-event, become part of the cohort requiring supports for their complex needs.

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.

### **CLINICS SERVING INDIVIDUALS 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, nonprofit agencies supporting people with disabilities have stepped up to ensure their access to health services across the State through an array of Article 28 & Article 16 clinics. These clinics have evolved to become true specialty service providers, serving patients with the highest needs and often at a financial loss. With OPWDD/DOH rate reform removing any surpluses in other programs, which had helped providers to subsidize these clinics, the insufficient funding of disability clinical services has been glaringly exposed. The annual 20% losses on clinic operations can no longer be sustained and Boards across New York State are facing tough decisions about the future of these clinics.

To date, when Boards choose to close clinics, patients, in most instances, have no good option. In the absence of primary care, dental patients are forced to seek treatment in the ER or schedule operatory time for procedures that easily could have been avoided. Generally, 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 situation is leading us in exactly the opposite direction from the one New York State has been promoting. In order to prevent New York State from incurring unnecessary Medicaid costs, we recommend the State invest in these specialty clinics and recognize them as an essential part of the service delivery network.

### **OPWDD TRANSFORMATION**

While a system-wide restructuring is on-going, this year's Executive Budget fails to support it. Unlike the hospitals, and to a lesser extent other health care providers, which have received billions of new dollars to support their transformation, only \$5 million has been allocated in this year's Executive Budget to support the OPWDD Transformation Agenda and nothing to support IT/infrastructure development. Successful transition to Care Coordination Organizations and Managed Care requires investment. We have never had the IT framework, the data warehousing, electronic health records and reporting capabilities required to transform into a Medicaid managed care system. Again, building this infrastructure is expected without any additional investment and far fewer dollars than existed eight years ago. Without your assistance and support, the prospects are bleak that our future will include a fiscally viable network of supports and services for people with I/DD. The lack of State investment must be evaluated as we look ahead to further "system transformation."

### **CONCLUSION**

With your support, including continued investment toward a living wage for our lowest paid workers, we can accomplish our mutual priority of maintaining and enhancing supports and services for New Yorkers with I/DD and their families. We can redesign the system, create efficiencies, provide necessary supports to people when and where they need them and continue to be known as one of the best states in the country for all people, including those with intellectual and developmental disabilities. COPA would like to thank the Legislature for its ongoing support, and we look forward to continuing to work with you on behalf of people with I/DD in New York State.