



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**

**2018-2019 Executive Budget
Mental Hygiene**

Presented by

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&

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The InterAgency Council of Developmental Disabilities Agencies

For the Coalition of Provider Associations

February 13, 2018

Representing More Than 250 Providers in New York State

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Good afternoon Committee Chairs Young, Weinstein, Ortt, and Gunther, 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 2018-19 budget proposal.

I am Barbara Crosier from Cerebral Palsy Associations of New York State (CP of NYS) joined by Wini Schiff of the InterAgency Council of Developmental Disabilities Agencies (IAC). 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 (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 hundreds of thousands of 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 commitment to the #bFair2DirectCare initiative and our workforce. We seek your continued support and investment in a living wage for Direct Support Professionals, 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 budget has remained flat over the past six years. In each of the past five 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 2018, ATL spending on OPWDD programs was \$88 million less than FY2017. For FY 2019, proposed spending is \$151 million higher, but due to these mid-year adjustments, even with this addition, there has been a cumulative reduction in spending over the past 7 years of \$53 million.

In addition, while actual spending has been reduced each year, there has been no Medicaid Trend for inflation since 2010. While we were more than appreciative of the increases for certain staff salaries in 2015 and 2018, 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), 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 including tenuous provider fiscal health and the inability to pay adequate salaries to attract workers to fill vacant positions.

While there has been a lack of recognition of cost increases in operations, our system has also 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) 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 these programs that cannot sustain themselves, reducing access to services and penalizing providers which support the higher cost individuals. We look to the Legislature to work with us and the funding agencies to review the impact of the reimbursement policies of SED, OPWDD and 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; and all of this with reduced funding.

DSP LIVING WAGE

The Office for People With Developmental Disabilities (OPWDD) Aid to Localities budget includes \$44 million to continue to provide funding to implement the new minimum wage, but more importantly, \$145.8 million 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 look forward to New York State's continuing support as we take future steps to reach our living wage goal. Our recently updated survey of providers across the State shows that for 2017, vacancy rates have increased to 14.4% (an increase of 30% from 2016) and the turnover rate has increased to 26.7% (up 7.5% from 2016) causing providers to pay over 10 million hours of overtime and with a cost of approximately \$29 million to replace lost staff (when even possible).

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 more than 80% of 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.

Therefore, while we originally thought that we could phase in the living wage (\$17.72 downstate and \$15.54 for the rest of the State) over six years, we now urge the Governor and Legislature to support a shorter time frame for the plan, condensing the remaining increases into three additional payments this, and the next budget year. 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 worsening at an alarming rate, and we urge you to continue your support for #bFair2DirectCare by adding \$18 million beginning 1-1-19 to move our low wage workers one step closer to a living wage.

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.

Therefore, after so many years of flat funding and reductions, even the most optimistic allocation is woefully 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 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. 424 new certified opportunities have recently been released, reportedly based on current need. We are certain that there are many more individuals who currently have urgent needs for certified residential opportunities and who would have been on the list if they had access to/knowledge of the CRO system. We are concerned that over-reliance on potentially inaccurate ISPM scores as a way of determining need could be another factor in limiting access to housing. Further, we ask that there be more transparency about the lists/numbers of people seeking residential supports, in general.

We understand that "backfills" are a significant source of certified housing opportunities. When the opportunity available matches the needs of the individual seeking this option, then backfilling works! When it doesn't, frustrating and possibly dangerous situations can result. Many in need of placement are medically frail or have significant behaviors which require enhanced staffing not available in the typical backfill opportunity. Many people with intellectual and developmental disabilities also have a mental health diagnosis, yet we have difficulties blending available funds for capital development projects or ongoing supports. When individuals and/or families choose not to accept a backfill opportunity, usually because it is inappropriate, they are often moved to the back of the list, increasing their wait time for needed residential services. 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. Many people are aging in residences developed many years ago that can no longer meet their needs without significant capital work or

relocation for which OPWDD funding is at best limited or no longer available. We need to provide modifications and/or supports for those who want to age in their homes in a way that fits within individual goals and preferences. 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.

TELEHEALTH/TELEMEDICINE

In his recent State of the State Address, Governor Cuomo recognized the critical need for telehealth services and stated that it can overcome substantial cost barriers to care. He proclaimed that “New York will take steps to modernize the delivery of telehealth services” and that current state law is “outdated” and restricts settings in which patients can access telehealth services.” This critical initiative recognizes that telemedicine has the ability to significantly enhance the quality of care for people with developmental disabilities, provide significant Medicaid savings through reduced Emergency Room visits and hospitalizations and reduce stress for our workforce. A pilot program by CP of NYS concluded that 86% of ER visits could be avoided with telemedicine. This proposal is aimed at further expediting the Governor’s laudable goal of implementing a comprehensive system of telehealth services.

Therefore, in order to provide telemedicine for individuals with developmental disabilities, which will provide significantly better care and Medicaid savings, it is critical that OPWDD promulgate regulations in a timely manner and provide funding for I/DD not-for-profit agencies to purchase telemedicine equipment that don't have Article 16 or 28 clinics and to the DOH Health Care Facility Transformation fund.

Telemedicine for individuals with I/DD is truly a win-win for everyone.

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, no new funding has been allocated in this year’s Executive Budget to support the OPWDD Transformation Agenda. Successful transition to Care Coordination Organizations and Managed Care requires investment.

Examples of this failure include:

- Discontinuation of the State supplement for providers converting and downsizing ICF's to IRA's;
- Inadequate funding to move to electronic records;
- Inadequate funding for self-direction.

We also believe OPWDD and the Executive Budget have grossly underestimated the cost and complexity of self-direction and that there is an over emphasis on this model. While an increased number of families are interested in exploring self-direction, the Executive Budget fails to make the necessary investment to allow individuals to purchase the basic array of services to live a fully independent life. The skills and time needed to manage this service delivery model are burdensome or impossible for many families, especially those with stressors above and beyond caring for an adult child with I/DD including poverty, illness, and lack of education. And most importantly, we know there is an increasing shortage of qualified staff to provide the services given their inappropriately low pay. Without staff there are no services.

UNFUNDED MANDATES/OTHER SYSTEM COSTS

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 . As noted previously, hospitals have perennially received funding for infrastructure needs, whereas our system has not. 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. 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 drastically cut. 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.