



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**

**2017-2018 Executive Budget
Mental Hygiene**

Presented by

Winifred Schiff
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For the Coalition of Provider Associations

February 6, 2017

Representing More Than 250 Providers in New York State

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Good afternoon Committee Chairs Young, Farrell, Ortt, and Gunther, members of the Senate Finance Committee, Assembly Ways and Means Committee, and the Mental Health and Developmental Disability 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 2017-2018 budget proposal.

I am JR Drexelius of the Developmental Disabilities Alliance of Western New York (DDAWNY). I am joined by Barbara Crosier from Cerebral Palsy Associations of New York State (CP of NYS). Wini Schiff of the InterAgency Council of Developmental Disabilities Agencies (IAC), who was to present this testimony, has a family issue she is dealing with and regrets she cannot join us. 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) – because people with disabilities, their families, and the organizations that support them are increasingly frustrated by over \$600 million in State funding cuts over the past six years and the lack of investment in our workforce and supports and services. These cuts have caused layoffs of staff, the reduction and elimination of supports and services, and long delays for those seeking entry into programs. These actions create serious barriers for some of New York's most vulnerable citizens. COPA represents over 250 not-for-profit agencies across New York State that 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 seek the Legislature's support in working with us to invest in and prevent any further erosion of supports and services to individuals with I/DD and their families that New York has had such a proud history of providing. We have come too far as a State to allow this and we must all continue to honor the promises made.

OPWDD BUDGET BACKGROUND

The Office for People With Developmental Disabilities (OPWDD) Aid to Localities budget has been reduced over the past six years, and even with the proposed increase for 2017/18, is budgeted to be virtually flat, despite the fact that OPWDD services are almost exclusively funded by Medicaid with a 50% federal match. All Medicaid spending included in the Department of Health's Global Medicaid Cap has grown approximately 3.7% per year over this same time period, or almost 22% during the same period. In three of the last six years, state share spending has been cut, by over \$100 million (-\$128 million in FY13, -101 million in FY14 and -\$102 million in FY16). Over the past four years, state spending reductions have totaled a loss of-\$111 million. Even with the proposed FY '18 Local Assistance spending increase of \$105

million, State Share Local Assistance spending represents a -\$6 million loss over five years and is \$134 million less than actual FY '12 state share cash disbursements.

The bottom line is that for the past seven years, the OPWDD budget has been at best flat and has included zero dollars for inflation while at the same time costs to meet the basic needs of individuals we support continue to rise. The cost of workers comp, liability insurance, employee health care costs, which have risen nearly double digits annually for many agencies, and the myriad other fixed costs remain flat.

Additionally, the State has failed to provide enough funds to allow our agencies to attract and retain a quality work force. We hear claims of years of robust spending and a 3.3% increase this year, yet the reality is that the FY '18 Executive Budget proposes to spend \$134 million less than was spent by the State seven years ago. The not-for-profit community is serving many more individuals with significantly less State funding. The current fiscal year spending proposal adopted last March, promised a \$141 million increase in state share cash disbursements over FY' 16 state share cash spending. The reality is that the current fiscal plan will only spend \$10 million more than FY'16. Where our starting salaries at one time were three or four dollars higher than the minimum wage, we are now unable to pay, even our seasoned staff, much more than the minimum. The proposed budget also eliminates the 0.8% Statutory Human Services COLA for this year. We are being starved. With an average current vacancy rate of over 11% (a 43% increase from two years ago), our ability to provide services has reached a crisis level.

During the first five years of the Cuomo Administration there were cuts of \$259 million and an additional \$121 million in cuts in the prior Administration. The last inflationary increase for OPWDD not-for-profit providers was given in 2010-11, except for a targeted 4% increase effective 1/1/15 (2%) for direct support staff; and 4/1/15 (2%), for direct support staff and clinicians. Therefore, lost inflationary increases over the previous five years, net the 2016-17 COLA of two tenths of 1%, total \$562 million. Providers of supports and services for individuals with I/DD are facing the continuing rising cost of providing services, 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 and are in the midst of a system transformation, all with reduced funding by almost a billion dollars (as outlined above).

DSP LIVING WAGE

COPA is extremely supportive of 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 the Direct Support Professional Alliance of NYS and the Self Advocates Association of NYS) to form the #bFair2DirectCare Coalition. We are all bewildered as to how the State of New York could possibly uphold its statutory obligations to support individuals with I/DD when the Executive Budget provides no funding to increase the salaries of those

providing direct support to individuals with I/DD, beyond funds to support bringing very low-wage workers to the new minimum wage standard.

These are not minimum wage jobs! Direct Support Professionals deserve a living wage and we urge you to support the #bFair2DirectCare Coalition's call for an investment of \$45 million a year for the next six years, to be matched by federal funding in order for us to be competitive with other businesses and attract and retain the best and most compassionate workers.

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. Providers already face a workforce crisis, some with direct care staff vacancy rates of up to 20 percent due to the low wage and challenging nature of our work. As a result, we pay millions of hours of overtime each year and many shifts are beginning to go unfilled.

We, as a state, face troubling choices if we won't pay our workers a living wage. As our ability to attract and retain qualified staff deteriorates, our vacancy rates will soar, incidents which endanger the welfare of the people in our care will increase due to lack of qualified staff, and the qualified ones who are left will experience "burn-out" due to the burden of increasing overtime hours worked. In short, 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 non-profit, community-based organizations.

Funding the minimum wage is not enough. These are clearly not minimum wage jobs and failing to recognize this is reckless. We urge you to support the #bFair2DirectCare campaign and join us in stating, "*we can think of few workforces more worthy or important to our state and communities and ask the Legislature to do the right thing and #bFair2DirectCare.*" Doing the "right thing" requires the investment of \$45 million in this budget to begin funding a living wage for these everyday heroes.

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 \$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 know that the needs of individuals with disabilities must be met with a wide range of choices for people with I/DD in where they live, work, and otherwise participate in the community. COPA believes that the budget contains unrealistic expectations regarding the number of individuals for whom low cost services are appropriate. The Executive Budget proposal fails to recognize that a significant portion of the population OPWDD serves will need greater supports than are available through supported employment and other lower cost options. These individuals will require the more intensive support available in, for example, day habilitation or pre-vocational services. This further illustrates the inadequacy of the Governor's proposal for new supports and services.

We support the inclusion of \$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. At the current time there is a critical need for additional supportive housing opportunities for persons with I/DD, and although this is a good start, more progress needs to be made in this area. We welcome the inclusion of the I/DD population among the groups eligible for the State's affordable and supportive housing funds within the Department of Housing and Community Renewal and hope that the final budget includes an adequate allocation set-aside specifically for people with I/DD.

In addition to capital funding, 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 and we strongly support the additional funding included in the Governor's proposal to expand the START program in the downstate region. Much more, however, is needed.

OPWDD TRANSFORMATION

This year's Executive Budget fails to support a successful restructuring of the system. 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 beyond covering the lagging payments for services as we move from fee-for-service to a new Managed Care payment system. These are being completely ignored in the Governor's proposal.

Examples of this failure include:

- Lack of funding to downsize ICFs as required by CMS.
- Inadequate funding to move to electronic records.
- Inadequate funding for self-direction.
- Lack of funding for the establishment of Conflict Free Case Management entities to replace Medicaid Service Coordination as it is currently delivered (there is language in the budget to provide \$5 million for this purpose in 2018 but the implementation date for this transformation is December of 2017).

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 there is an increase in the number of families interested in exploring self-direction, the Executive Budget fails to make the necessary investment to allow individuals to purchase even the most basic array services to live a fully independent life. The skills and time needed to manage this service delivery model are burdensome 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.

JUSTICE CENTER /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 paperwork and system approval processes that are continuously being added. 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 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 seven 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, and the Justice Center have grown steadily at the same time that our funding has been drastically cut. The return on the investment the State has made in the Justice Center must be evaluated as we look ahead to further "system transformation."

The New York State Justice Center for the Protection of People with Special Needs

Non-profit providers of supports and services for people with intellectual/developmental disabilities supported Governor Cuomo's establishment of the New York State Justice Center for

the Protection of People with Special Needs (Justice Center) as it was based on Clarence Sundram's report and goals that they heartily endorsed. Unfortunately, the implementation of the Justice Center has had the opposite effect of Mr. Sundram's intent and the agency's stated mission. At the same time that non-profit providers have seen almost \$400 million in cuts and more than \$560 million in lost inflationary increases, the Governor has requested \$149.1 million for the Justice Center, an additional \$54 million for the 2017-2018 state fiscal year. COPA, working together with all of the developmental disability associations, surveyed the impact of the Justice Center on supports and services for people. The report, *The Justice Center: Opportunity Missed*, clearly articulates the detrimental effect that the Justice Center has had on the staff, supports and the individuals that it was established to protect. The COPA report asks for a thoughtful examination and evaluation of the Justice Center with an eye on its impact on the human services provider community. Not-for-profit organizations seek broad fundamental changes in the Justice Center's mission and function with a focus on quality assurance activities, development of best practices, and education. The report is intended to prompt a collaborative discussion with the Legislature, the Executive, advocates and not-for-profit providers, to seize the opportunities missed by the Justice Center's implementation to date. COPA urges you to read our report and to contact us with any questions and concerns.

CONCLUSION

With your support, including a new \$45 million investment as a first step toward a living wage, we can accomplish our highest priority; to increase the salaries of our hard working but low paid direct support staff. We can successfully redesign the system while expanding the availability of supports for people with I/DD. But none of this can be done without the real commitment of New York State.

COPA would like to thank the Legislature for its ongoing support for people with I/DD. We look forward to continuing to work with you on behalf of people with I/DD in New York State.



Alliance of Long Island Agencies (ALIA)
Cerebral Palsy Associations of New York State (CP of NYS)
The Developmental Disability Alliance of Western New York (DDAWNY)
Direct Support Professional Alliance of NYS (DSPANYS)
The InterAgency Council of Developmental Disabilities Agencies (IAC)
The NYS Association of Community and Residential Agencies (NYSACRA)
NYSARC Inc.
New York State Rehabilitation Association (NYSRA)
Self-Advocacy Association of NYS (SANYS)

TESTIMONY SUBMITTED TO THE NEW YORK STATE LEGISLATURE
Joint Hearing of the Senate Finance and Assembly Ways and Means Committees

2017-2018 Executive Budget Proposal

Mental Hygiene

Monday, February 6, 2017

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

It's been almost a year since seven associations, which has grown to nine, whose hundreds of members are the not-for-profit organizations that provide supports for New Yorkers with Intellectual and Developmental Disabilities, came together to start a campaign for a living wage for our direct support staff.

At the time we didn't have a name for our campaign and we weren't sure how we were going to work together, but today we come before you and we have a name, #bFair2DirectCare, and a clear message: A living wage for direct care workers will allow New York State to show the whole country that we are accepting of all and have and will continue to make the investments needed to show the strength of our values.

The investment is \$45 million a year for the next six years, to be matched by federal funding. It is a modest request in the context of a New York State Budget of more than \$150 BILLION!

We have taken our campaign and its very basic message from Buffalo to Brooklyn, from Suffolk to Syracuse, and all parts in between.

The #bFair2DirectCare campaign represents a half million New Yorkers who see their quality of life threatened – people who benefit from the staff support that allows them to maximize their abilities and live lives that most of us take for granted. We represent the family members who provide tremendous and lifelong support, but can't do it alone. We represent the Direct Support Professionals (DSPs) who struggle to support their families and want to keep working with people with developmental disabilities, but lack a decent wage.

We've been joined by a majority of state Legislators – some of whom have family members with developmental disabilities, others who value our work and value keeping the people we support in the community and out of institutions.

At rallies, press conferences and in meetings, our campaign name says it all: Please be fair to the direct care workers so many of us depend upon. Please let us keep the best and most compassionate workers by funding a living wage that allows us to be competitive with other businesses.

There are many Americans who wonder about the future direction of our country and how it treats people who are vulnerable. As the old activist saying tells us, we need to "Think globally but act locally." This is our chance to show our support for people with developmental disabilities whose lives will be diminished by inaction as the support they need falls apart.

Collectively, a little snapshot of what it will cost to be fair to direct care and why the investment is both necessary and overdue is as simple as: "We get more than 90% of our funding through Medicaid and other government sources and the majority of our funds go to direct care staff compensation. Medicaid rate increases to cover wage hikes have been frozen for seven of the eight most recent years. We are not-for-profit community based organizations and our jobs used to be good jobs, but they have lost their purchasing power, and in many cases now start at or just above minimum wage. When these were competitive jobs, people stayed with us in the jobs they loved, serving and supporting New Yorkers who are living their life to an extent once thought impossible. The people we support, their families and our workers are our families, friends and neighbors. They are part of the fabric of our communities and they help make New York the greatest state in the Union."

Today, we come before you facing a staffing crisis, not of our making, but one that gets progressively worse because of the stagnant rates the state pays us. As our salaries grow less competitive, our DSPs are leaving because they can earn more by taking a job in a fast food restaurant or big box store. Many DSPs are working two or three jobs, struggling to support their families and some work full time and still qualify for food stamps. This should be unacceptable anywhere, but especially in New York.

A look at our last three years' vacancy rates show more than 10% of our direct support jobs are vacant and that percentage is increasing:

- 2014 DSP vacancy rate = 7.76%
- 2015 DSP vacancy rate = 9.3%
- **July 1, 2016 DSP vacancy rate = 11.08%**

Vacant jobs mean gaps in coverage that have to be filled with overtime – for now at least. Our provider organizations count the number of hours of overtime used in the millions of hours – more than 6.4 million hours in 2015 alone for providers that responded to our survey – an increase of 13.5% more than the 5.6 million hours of overtime in 2014.

In 2017 we have reached the point where overtime can't keep up and we will have to start looking at which programs will have to be cut out – unless you act and convince Governor Cuomo to provide funding for a living wage for DSPs in the 2017-18 state budget.

Additionally, the lure of easier work at better pay because of wage mandates in other service jobs is causing us to turnover employees at an alarming rate. More than 20% of new staff hires leave within a year.

More important than adding to our staffing problem, the people we support can no longer count on seeing a familiar face day after day as people who support them leave for better pay and better hours (DSPs work 24-7-365). This has terrible consequences for people who are best supported through routine, love their staff like family, and in some cases have limited ability to communicate. To someone who can't speak, having a staff person who has learned how to recognize distress could be the difference between a fulfilling day and needless suffering.

We as a state and a caring community face some stark consequences if we can't pay our workers a living wage. First, more and more workers will leave and our staffing crisis will only worsen. Agencies' program vacancies will go unfilled. People will go unserved.

Some, and someday maybe all, of the not-for-profits that care for people with developmental disabilities on behalf of the state could close, requiring the state to take over care of thousands of people – at costs to taxpayers that are 40% more than what the state pays the not-for-profits.

What we need is 0.0288% of the total budget.

We can almost guarantee it that if Albany won't find the money now it will have to find a whole lot more money later.

The Governor would tell you that he has fully funded the minimum wage and that we can cut back on our executive salaries to fill the gap. We would tell you that he turned our good direct

care jobs into minimum wage jobs and as a result he needs to lift these important jobs back up to the status they had before the rate freezes and the wage mandates. We can think of few workforces more worthy or important to our state and communities and we ask the state Legislature to do the right thing and #bFair2DirectCare.

Don't hear it just from us, however. We have attached an op-ed recently published in the *Albany Times Union* by Margaret Raustiala, a parent from Long Island. Margaret is the mother of Riko, a 46 year old man with autism.

The Governor can still add these funds in his thirty day amendments and we ask you to join us in urging him to do so. Should that not come to pass, we are asking you to include \$45 million in state funds to begin to provide direct care workers a living wage in your chamber's one-house budget. Then we will need your help in fighting to ensure that it is in the final enacted budget.

We leave you with the words of an American with a disability, a former New York Governor, a U.S. President, and hero to us all. I hope they guide you in these uncertain times:

“By living wages, I mean more than a bare subsistence level — I mean the wages of a decent living.” (Franklin Delano Roosevelt 1933, Statement on National Industrial Recovery Act)

Thank you on behalf of the more than one-half million New Yorkers with developmental disabilities, their families and those who serve and support them.

Seth Stein, Alliance of Long Island Agencies for Persons with Developmental Disabilities

Susan Constantino, Cerebral Palsy Associations of NYS

Rhonda Frederick, Developmental Disabilities Alliance of WNY

Richard Bosch, InterAgency Council of Developmental Disabilities Agencies, Inc.

Jason Marlowe, Direct Support Professional Alliance of NYS (DSPANYS)

Ann Hardiman, NYSACRA

Steve Kroll, NYSARC

Michael Seereiter, NYSRA

Tim Tompkins, Self-Advocacy Association of NYS (SANYS)

timesunion<http://www.timesunion.com/tuplus-opinion/article/Invest-in-state-s-direct-care-work-to-avert-10880718.php>

Invest in state's direct care work to avert staffing crisis

By Margaret Raustiala, Commentary Published 4:10 pm, Tuesday, January 24, 2017

My son Riko is 46 and has autism. He is helped by workers employed by nonprofits that serve people with developmental disabilities.

Many people's knowledge of autism is based on Dustin Hoffman's Oscar-winning portrayal of autistic savant Raymond Babbitt in "Rain Man." But that's Hollywood. Riko enjoys music, walking outdoors and volunteering at a soup kitchen, but he needs a direct care worker to do any of these things.

Riko is one of 128,000 New Yorkers with developmental disabilities who often cannot speak for themselves and rely on direct care workers for their health and safety. This includes bathing, feeding, toileting, medication administration, teaching basic skills, ensuring community integration and crisis intervention.

More Information

Margaret Raustiala is a parent, retired coordinator of the Alliance of Long Island Agencies Inc. and a member of the #bFair2DirectCare Coalition.

For nearly a year, the #bFair2DirectCare Coalition — people with developmental disabilities, their family members, direct care workers and the agencies that employ them — has been asking Albany for the funds so our direct care workers can receive a living wage.

Staff shortages threaten the very community integration that's required by the federal government and exemplifies a quality system. Without adequate staff, Riko and others are virtually under "house arrest" in their group homes or day programs. With a vacancy rate of more than 10 percent and growing, and a turnover rate of more than 2 percent and growing, robust community integration programs threaten to disappear.

This burgeoning care and staffing crisis can be solved if Gov. Andrew Cuomo and lawmakers dedicate \$45 million year for the next six years, starting in 2017-18. That's

a small investment in a \$152 billion budget to avoid a crisis that has real-life implications for so many.

Sadly, Cuomo failed to provide any funding for a living wage in his budget proposal. We can't know what's in his heart, but we know what's not in his budget. And we know he is worsening a growing crisis. Ultimately, the state will need to take over care — a development that will be much more expensive for taxpayers.

Direct care work is not minimum wage work. It requires sophisticated skills, hours of training and the ability to handle tremendous stress.

Until a few years ago our nonprofits had been able to attract and retain workers by keeping wages higher than minimum wage. Recruitment and retention was a challenge, but we could handle it.

That all changed, with the one-two punch of stagnant rates and the increase in private sector wages mandated by Cuomo and the Legislature now under way.

As direct care wages continue to fall further behind wages in Wal-Mart, Target and Costco, our workers are faced with the difficult choice of keeping a job they love or earning enough to make a decent living.

Our hands are tied. We get 90 percent of our funding from government. Albany decide the rate. We can't raise prices or automate hamburger production. Direct care work requires people. Yes they have good heads and big hearts, but they have to feed their families, too.

I am frightened for Riko and other New Yorkers with developmental disabilities. Not only do they depend on their care workers, but they form important family-like attachments.

Just a few yards from Cuomo's Capitol office, there stands a display with a remarkable statement expressing New York's global standard for caring, compassion and justice. It's a statement our leaders should heed right now.

"In New York, I have called this 'The New York Idea': government using its resources to help create private sector growth, then requiring those who benefit from that growth to

share some part of it so that hope and opportunity are extended to those who have not been as fortunate. We do this so that we can take care of those who will never be able to care for themselves."

The author was Gov. Mario Cuomo.

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