



**TESTIMONY OF STEVEN KROLL  
EXECUTIVE DIRECTOR, NYSARC, Inc.**

**MEMBER OF THE #bFair2DirectCare Coalition**

**BEFORE THE NEW YORK STATE JOINT LEGISLATIVE HEARING  
OF THE SENATE FINANCE AND ASSEMBLY WAYS AND MEANS COMMITTEES  
ON THE FY 2017-18 STATE BUDGET**

**FEBRUARY 2017**

**I. EXECUTIVE SUMMARY**

- NYSARC, Inc. is the New York State Chapter of The Arc. With 47 Chapters across New York State, NYSARC supports more than 60,000 individuals, employs 30,000 people and has a membership of more than 100,000. NYSARC's mission is to advocate for and provide services to people with developmental and other disabilities in every manner possible. NYSARC is committed to a full quality of life for every person.
- The Executive Budget completely ignores the rapidly expanding workforce shortage that threatens services for New Yorkers with developmental disabilities.
- The State's plan for addressing the mounting list of people in dire need of residential services, including many people who can no longer be cared for by aging caregivers, will not make meaningful progress in reducing waiting lists. Thousands of families will continue to have little hope of finding the support they need.
- The "rate rationalization" provider payment system has robbed the developmental disabilities services system of the flexibility it needs to meet rising costs by deploying financial resources where they are needed most. It has also created incentives to operate less, not more, efficiently.
- The developmental disabilities service system is being asked to transform itself with little or no investment. Funding cuts, unfunded wage hikes, and rate rationalization have diminished the system's potential to meet transformation goals.

## **II. SUMMARY OF RECOMMENDATIONS**

### ***Direct Care Workforce Shortage***

- Appropriate \$45 million state share to fully fund the first year of a six year plan to increase the wages of DSPs and other low paid workers serving people with developmental disabilities to a “living wage.”
- Rescind the deferral of the Cost of Living Adjustment proposed in the Executive Budget and add language tying the annual Cost of Living Adjustment to the rate of medical inflation rather than the Consumer Price Index (CPI). Provide \$80 million to implement this in the FY 18 budget.
- Include budget language requiring OPWDD, in conjunction with relevant parties, to evaluate the relationship between staffing shortages, increasing levels of turnover and vacancy rates, and the incidence and cause of reportable incidents.

### ***Waiting List for Services***

- Appropriate \$100 million state share (\$200 million total) to provide additional placements for people living at home in need of out of home residential care.
- Implement a new fair and transparent caregiver assessment process to determine need and connect/approve people living at home with needed services before their situation becomes emergent. This process must take into account the individual’s needs, the ability of family caregivers to provide continued care, and the length of time family caregivers have cared for their loved one, among other relevant factors.

### ***Schools for Children with Developmental Disabilities***

- Require a 4% growth factor for 4410 preschool program rates.
- Support a set-aside of Universal Pre – K monies for 4410 Schools.
- Appropriate \$18 million for a teacher recruitment and retention program for 4410 preschools and Chapter 852 schools.
- Support the NYS Association of Counties proposal to gradually eliminate the county responsibility for 4410 preschool costs.

### ***Fix Fundamental Flaws in Rate Rationalization***

- Fix rate rationalization by:
  - allowing for a rate of return;
  - not penalizing efficiency;
  - appropriating \$23 million for a SEMP (supported employment) contingency fund; and
  - reimbursing providers for snow days, flu days, other unavoidable program closures and participant absences, and other extraordinary and unavoidable expenses that are required and not paid for.

### ***Funding for System Transformation***

- Enact budget language giving developmental disabilities services providers access to the \$500 million Health Care Facilities fund included in this Executive budget. Such funds will help meet the goals of federally and state mandated transformation to smaller, more integrated, and person-centered settings and to achieve program efficiencies to generate savings to reinvest into services through enhanced information functions, sharing of services, and mergers and consolidations. Billions in similar funds (e.g. Health Care Facility Transformation and HEAL Grants) have been appropriated to achieve efficiencies in the state's health care system. The needs of the developmental disabilities system should be accorded similar recognition.

### **III. A BUDGET IS JUDGED BY BOTH WHAT IT DOES AND WHAT IT DOES NOT DO: HERE IS WHAT'S IN AND WHAT'S NOT IN THE EXECUTIVE BUDGET**

#### **KEY ITEMS IN THE BUDGET INCLUDE:**

- **DEVELOPMENT OF NEW SERVICE OPPORTUNITIES:** \$120 million (combined federal and state share) for new development for an unspecified number of mostly residential opportunities for people living at home. Further, flexibility provisions allow some of these funds to be diverted to other unspecified needs including provider stabilization and managed care start-up expenses.
  - *There is little to no detail to allow NYSARC to assess the potential for providing much needed funding for provider stabilization or managed care readiness. In addition, this budget pits development of new service opportunities against provider transformation, when the total funding allocated is less than is needed for either purpose.*

- **START:** \$21 million for the Systematic, Therapeutic Assessment, Respite and Treatment (START) program to improve implementation of behavioral health supports. This funding will continue the expansion of the START program into the downstate area.
  - *NYSARC strongly supports the expansion of the START program, which can improve the quality of supports for people with behavioral health needs, as well as lower the cost of intervention. NYSARC would urge even faster implementation through a higher funding level.*
- **AFFORDABLE HOUSING:** \$15 million for affordable housing to provide independent living situations for people with developmental disabilities.
  - *The need for affordable housing funds is so great that this is only a small amount of what is needed to help people with developmental disabilities live in community settings.*
- **MINIMUM WAGE FUNDING:** The budget includes \$14.9 million to fund scheduled minimum wage increases in the field of developmental disabilities which took place on December 31<sup>st</sup>, 2016 and increased the minimum wage to \$9.70 upstate, to \$11.00 in NYC and \$10.00 on Long Island.
  - *These funds bring all employees up to the minimum wage. But, a minimum wage is not a living wage and this budget does not support salary increases for those above the minimum wage. Under this budget a DSP earning \$9.70 an hour on January 1, 2017 will still earn \$9.70 an hour in the next fiscal year.*
- **DEVELOPMENTAL CENTERS:** The budget includes \$24 million to transition individuals out of developmental centers and various Intermediate Care Facilities (ICF) into less restrictive settings.
- **LANGUAGE AUTHORIZING THE WITHHOLDING OF FUNDS:** Language to authorize the Governor to withhold funds in the event that federal receipts fall short of amounts specified in the state financial plan. According to the Division of the Budget, this language was included due to the high level of uncertainty surrounding the change of Administrations in Washington.
  - *NYSARC believes that this would be an extraordinary shift in state budget responsibility. Should federal actions necessitate budget modifications, they should be the product of the joint work of the Governor and the Legislature.*

- **PRESCHOOL:** Language in the Executive Budget presentation refers to the development of an alternative funding methodology to enhance the state's ability to deliver services in integrated classrooms.
  - *Integrated classrooms are a vital feature of special education programming and NYSARC supports developing an improved funding methodology.*

**KEY ITEMS NOT IN THE BUDGET INCLUDE:**

- **FUNDING FOR THE #bFair2DirectCare LIVING WAGE PROPOSAL:** No funding was included in the Governor's budget request to recognize the needs of Direct Support Professionals and other direct care staff. This omission is especially painful in light of our two year campaign to educate and inform the public and public officials, in particular the Governor's Office, of the dire consequences of insufficient pay for adequate recruitment and retention of a quality workforce.
- **ADEQUATE DEVELOPMENT FUNDING:** Funding for new services is wholly inadequate to make any meaningful progress in eliminating a growing waiting list. Almost 11,000 individuals were on the residential request list as of July 1, 2016.
  - OPWDD has indicated that over the next three years approximately 6,300 residential slots could be filled.
  - OPWDD estimates that approximately 1,700 openings occur in existing residential settings each year without new investment, which would equate to 5,100 openings over three years. Therefore, OPWDD does not expect the system to grow by more than 400 residential slots per year, despite a waiting list of over 10,000.
  - It is important to remember that the waiting list is not stagnant; children with developmental disabilities grow into adulthood, family situations and other circumstances will change, and the residential request list will continue to grow.
- **TREND FACTOR:** The statutorily required trend factor was deferred until next fiscal year, FY 19.
- **PRESCHOOL GROWTH FACTOR:** The budget includes no 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.

- **RATE RATIONALIZATION FIX:** The budget makes no attempt to fix the system of rate rationalization or to fund shortfalls in the supported employment (SEMP) program.
- **JUSTICE CENTER REFORM:** No proposed Justice Center reforms.
- **FUNDING FOR TRANSFORMATION:** The budget includes no funding to help providers and the state comply with extensive federal Home and Community Based Setting (HCBS) requirements. The budget also contains no new funds for readiness for managed care.

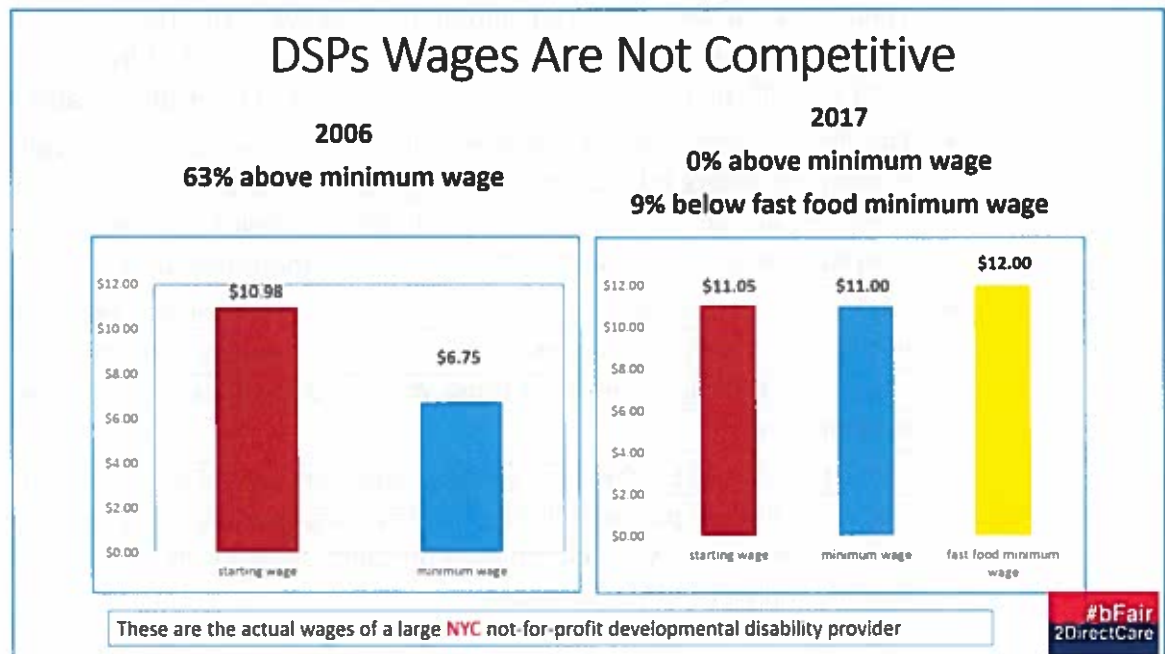
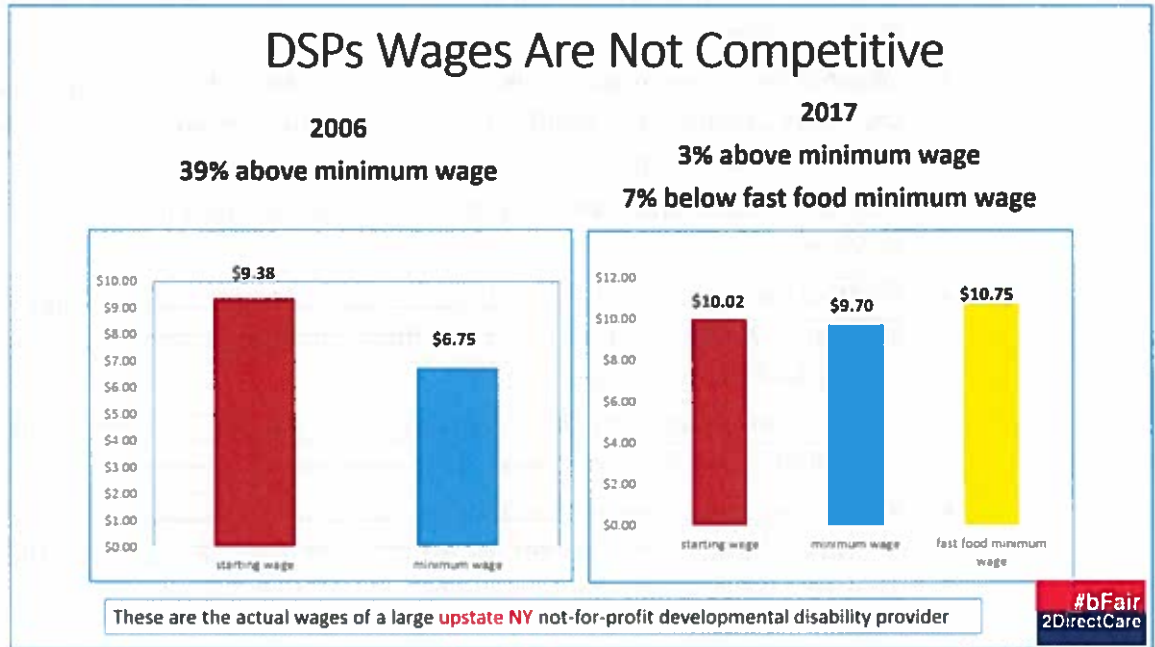
#### **IV. CHALLENGES FACING THE DEVELOPMENTAL DISABILITY SYSTEM – A STARKLY NEGATIVE OUTLOOK**

##### **1. WORKFORCE RECRUITMENT AND RETENTION**

###### **Direct Support Professionals (DSPs)—The Backbone of the System: Overworked and Underpaid**

- The testimony of the #bFair2DirectCare Coalition is attached to this testimony and is strongly endorsed by NYSARC.
- The Coalition is requesting an investment of \$45 million a year for the next six years, to be matched by federal funding to move DSPs and other vital direct care staff towards a living wage.
- A look at our last three years vacancy rate shows 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%**
- DSPs work long hours and provide support 24 hours a day, seven days a week.
  - DSPs teach essential living skills, supervise daily activities, assist with personal hygiene, meal preparation, manage toileting and 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. They must gain and maintain detailed knowledge of the specific needs of each person for whom they care.

- DSPs are responsible for providing services in a highly regulated environment that is closely scrutinized by state regulatory bodies and are held to the highest standards of accountability
- The following charts provide two real life examples of how DSP wages have lost their purchasing power and are no longer competitive.





## **2. WAITING LISTS: NOT ENOUGH OPPORTUNITIES -- ANXIETY AND UNCERTAINTY FOR FAMILIES**

- The number of adults with disabilities living at home who can no longer be cared for by aging family caregivers appears to have reached crisis proportions. Many of these adults living at home have severe disabilities including behavioral challenges, and almost 50% of people on the waitlist need help with almost all basic activities.
- Without significant new development, only individuals facing the most severe crisis fact patterns (e.g. death of caregiver or homelessness) will be likely to secure residential opportunities.
- Almost 11,000 individuals living at home have indicated interest in residential services.
- OPWDD has indicated that 1,300 people moved to certified settings from July 2015 to July 2016. Just under half of those individuals came from home and 80% were priority one emergency need.
- It is not clear how many other families on the waiting list need services immediately and how deep their crisis must be to be served.
- NYSARC does not believe the death or permanent disability of the caregiver, for example, should be the trigger for establishing need. Parents and their children deserve a reliable and stable planning process that secures residential support for their children.
- The current system leaves parents terrified about what will happen to their children, an anxiety no parent should have to live with. The current system and funding levels leaves people on the priority 2 and priority 3 lists (non-emergent) with virtually no realistic opportunity at housing in their foreseeable future.
- Families deserve to know that their adult children are safe and loved in a new home long before it becomes an emergency. Further, they deserve the predictability of a system that they will address their long-term needs, so that they need not worry about what will happen when they are gone.
- CMS also requires that people with I/DD be given a choice in residential settings in the least restrictive placement and OPWDD provides very little in the way of choice as basic placements for those who need them cannot even be accomplished.
- While the sum of \$120 million (federal and state share) is included in the Executive Budget proposal, it must satisfy a multitude of purposes, included the development of new developmental disability services. It is likely much of this funding will go to other purposes.



- Families are still fighting to get services approved in a system that will not allow the substantial and necessary expansion of capacity and is structured to only help people after a tragic event occurs or is imminent.
- NYSARC supports, at a minimum, the spending of \$100 million state share (\$200 million total) in this budget to provide additional placements for people living at home and in need of out of home residential care. In addition, a comprehensive long-term solution is necessary to bring the waiting list down to zero over several years.
- In addition to the need for additional resources, there should be a clear, transparent, and uniform statewide process for allocating residential placements that ensures fair and compassionate assistance for families. Combined with new funding for the substantial development needed, this will help bring about the commitment that New York families deserve.

### **3. FIXING RATE RATIONALIZATION'S FAILURES**

- Rate rationalization – implemented by the NYS State Department of Health – has eliminated the ability of providers to offset losses in one program by realizing efficiency savings in other programs.
  - As examples, providers that operate either clinics, workshops or supported employment programs that are under-funded have been keeping such programs afloat by creating savings in programs subject to rate rationalization. Use of such savings to avoid program closure must not result in a rate cut in the program from which the savings was created.
- The practice of basing future rates on a prior cost experience, unless such costs are trended, fails to account for both routine increases in operating costs (e.g. 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 an assumption that the provider will perform at one hundred percent capacity. When this proves impossible, mostly due to factors beyond the provider's control, the program will operate at a deficit.
- Provider representatives are working to convince DOH to make necessary changes in the rate rationalization methodology to support the need for resource flexibility. NYSARC believes that if appropriate changes are made we can avert the grave potential for crises that would occur if rates are otherwise cut upon rebasing in July.
- Unless a critically important change is made in the methodology prior to the upcoming July 1, 2017 rebasing, many providers that did the right thing by keeping underfunded programs open will be forced to close such programs.

#### **4. PRESCHOOL FUNDING**

- Chapter 4410 preschool programs provide critical services to children with disabilities ages 3-5 and their families. Programs have received two 2 percent 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.
- We project that without growth factors and necessary changes in the tuition methodology, nine of NYSARC's remaining 19 comprehensive 4410 preschool programs will be faced with imminent closure.
- No additional funding for preschool programs is contained in the Governor's budget request.

#### **5. EMPLOYMENT TRANSFORMATION**

- The State, with input from individuals, families and providers, has developed a plan to allow former workshop facilities to remain open as integrated businesses.
- Transforming into an integrated business will require employment of additional non-disabled co-workers. This will require development of additional and new products and lines of business.
- Most sheltered workshops already operate in deficit and expansion of the work they perform is likely to increase these deficits.
- Without financial assistance from the state many of these new integrated businesses will fail, which will jeopardize ongoing employment for the individuals with developmental disabilities they support.
- The plan has been submitted to the Centers for Medicare & Medicaid Services (CMS) for approval. However, CMS will likely take time to respond as it adjusts to the new Administration.

#### **6. JUSTICE CENTER**

- The Justice Center has inundated providers and DSPs, in particular, in voluminous paperwork, duplicative reporting responsibilities, and unnecessary investigative exercises which have no payoff in enhanced protection or quality for the people they serve. Further, DSPs are sometimes subject to an indiscriminate and punitive system and sanctions out of all proportion to most allegations and infractions.

- The majority of Justice Center investigations seem to “criminalize” mistakes or errors rather than address dangerous workers in the system. This exacerbates the staffing shortages and vacancy crisis already present in our field. It subtracts from the hands-on care which is key to the safety and well-being of people with developmental disabilities.
- NYSARC has prepared a legislative proposal to reform the Justice Center to focus on catching criminals, not persecuting hardworking professionals.

## V. MANAGED CARE IMPLEMENTATION

- The Executive Budget proposal lays out a timeline for the transition of the OPWDD system to managed care.
- NYSARC has been involved in a number of OPWDD work groups to discuss development of Value-Based Payment (VBP), Care Coordination Organizations (CCOs), and ultimately managed care. Each of these processes is incomplete and there still is a paucity of information available to judge the feasibility of implementation and ability of provider organizations to participate.
- The underlying discussion of moving towards managed care fails to recognize the chronic and growing stresses on the not-for-profit provider field. The challenges caused by the inadequate rate rationalization system and workforce shortages, for example, have providers struggling to maintain programs. Asking providers to prepare for and enter a managed care system under these stresses is unrealistic and a formula for probable failure. Restoring the stability and sustainability of the field should be a pre-cursor to implementation of managed care.
- NYSARC firmly believes that a substantial state investment will be necessary to prepare providers for CCOs and managed care. Absent such investment, providers do not have the resources and bandwidth necessary to develop the necessary structures. The state spent billions of dollars helping the health care system prepare for managed care and outcome based systems. It is unrealistic to expect the developmental disability field to do such without similar consideration.



Member The Arc





**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)**

## 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 #Fair2DirectCare Coalition.

For nearly a year, the #Fair2DirectCare 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 20 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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