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## MANHATTAN DEVELOPMENTAL DISABILITIES COUNCIL

Kathy Kelly, Chair, c/o AHRC NYC, 83 Maiden Lane, New York, N.Y. 10038, (212) 780-2724;  
manhattanddcouncilchair@gmail.com; www.manhattanddcouncil.org

31<sup>st</sup> Annual Legislative Breakfast, March 8, 2019

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### WORKFORCE ISSUES

Presented by Marie Richardson  
Direct Support Professional



I met Queen in the late 80s. She was in Camp Oakhurst with my daughter. My daughter has sickle cell. It's been a lot for me. She had many hospitalizations. She is much better now. She has two kids. Queenie is friends with my daughter. She comes to barbecues and she came to my daughter's baby shower.

I love what I do. I love that I can help the children that cannot help themselves. That makes me feel good. And they do appreciate what I do. Truly, they are my children, my sisters. I've been with Queenie and her two roommates for 20 years. I feel very close to them. Our relationship is quite good, I feel like they are part of my family.

When one of the women requests for me to go with her to the gynecologist on my day off, I say ok. The women don't want someone new to watch them. They are embarrassed. If someone has a trip early in the morning, I spend the night in the residence, sometimes on my own time. On my days off I sometimes go shopping for them. I come in when my own kids are sick because I feel like I have a responsibility to them. I owe it to them. I feel like I have to be there. As long as there is transportation, I'll be there.

The hardest part of my job is that we need more money. Our salaries are too low. I don't have enough to pay my mortgage. I have to rent part of my house to complete the mortgage. I manage because I have overtime. When staff is out, I work overtime. Staff do leave because they can't afford to stay. It happens. So many have left that I don't even remember their names. They come and go, they come and go.

The pay is not enough. We need more money. We're doing a lot. We do a good job, too. We should get more money than McDonalds' workers. We do much more. We give medication. Medication is no joke. We have to bathe the women and dress them because some of them can't do that for themselves. They wouldn't survive without staff. They would not survive.



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### RESIDENTIAL SERVICES

Presented by Stacy Wright  
Sibling



My sister, Stephanie, came to live with me and my two daughters 2 years ago when my mother was hospitalized and passed away.

Stephanie is 56 and she lived with my mother all of her life. They were really joined at the hip. When my mom passed, I sat with Stephanie and my daughters, and I explained to her that her mommy was sick and went to sleep last night and didn't wake up. She said nothing. Total silence. No one was breathing. I asked if she understood what I said. She said, "Yeah, Mommy died." Then she cried for a few minutes and said "Ok. I'm finished. Mommy's in heaven."

Stephanie has intellectual disabilities and a lot of medical issues. She is legally blind and she's diabetic. She has a lot of eye drops and medication for her diabetes. She is now totally blind in her left eye. I can never leave her alone in the apartment because she can't see anything now.

One day Stephanie blacked out because her sugar dropped. She wouldn't wake up. I didn't know what to do. My mom had never taught me. I was so scared. I called 911. The ER doctor gave me a crash course on what to do until I was able to get her to her regular doctor.

Weekdays, I get up at 4 AM so that I have enough time to give her her eye drops and check her sugar before her bus comes to take her to her day program. Then I go to work. The home attendant picks her up from the bus. Both of my girls help. They are 22 and 28 years old. If I can't get off from work on time, one of my daughters will come in and give her her eye drops and check her sugar because the home attendant can't administer any medication. There have been days when the home attendant couldn't come or was late and I've had to leave my job and come home get my sister. I thank God every day that my boss is so understanding.

We're all exhausted in here. Everyone is totally exhausted. It's topsy turvy in here.

If God forbid something happens to me, what's going to happen to Stephanie? And what happens to my children—because she is not their responsibility. My girls are young ladies. I want them to live their lives. I want them to be free. I feel like I'm holding them hostage.

I'm desperate for Stephanie to be in a residence that can accommodate her. I want her to be happy and comfortable and I want them to be able to take good care of her.

I strongly prefer a Manhattan residence because I plan to take her home every weekend and I want to continue to go to her doctors' appointments. If she were in another borough, I'd have to take the whole day off to do that.

There's been very little development of new residences, and hardly any in Manhattan, because there's not enough money in the budget. Most Manhattan individuals end up in another borough because real estate is too expensive to develop new residences here. It's not fair to the families. Not fair to the individuals.

It's not like anyone wishes anything bad for special needs children and adults, but they are not a priority. But they are a priority for somebody: for the folks that have special needs people in their families. Our legislators should fight for more money for residential development for families like mine that are just an accident away from an emergency.

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### SPECIAL EDUCATION

Presented by Mark Gonsalves  
Parent



My name is Mark Gonsalves. My wife and I have two sons, Justin, who is 6 and attends public school, and Josh, who is 9 and attends an 853 publicly funded non-public, non-profit school.

When Josh was about 2 years old, we noticed some changes in him. We had him tested and it was determined that Josh was on the autism spectrum. We worked with the NYC DOE and they were able to place him in a 4410, a publicly funded non-profit special education preschool.

At Josh's previous preschool for children without a disability, the staff just didn't know how to reach him. We would find him sitting by himself staring out the window when we would arrive to pick him up. At his 4410 school, the staff understood Josh and he began to make progress. He started talking more, moving better, and interacting with others. The teachers, OT, PT, and speech therapists were all terrific at the school. They were in touch with what he needed.

During Josh's first year, his head teacher and social worker both left. During his last year, the student teacher became the head teacher and one of the other specialists left. The experience of the 4410 school was so valuable for Josh, but the turnover hurt him, and his progress stalled.

Teacher turnover in 4410 preschools is at 26%. With the NYC DOE adding seats for three- and four-year-olds, the DOE has been poaching teachers from the 4410 schools and offering significantly better pay and benefits, resulting in an acute shortage of certified teachers in 4410 schools.

When it was time for kindergarten, we took Josh for additional testing to see what was appropriate for him. He was placed in an 853 publicly funded non-profit special education school with 8 kids in his class along with one teacher, two assistant teachers and a tremendous support staff. Children attending 853 schools are placed there after

a determination has been made by the Committee on Special Education that the local public schools are unable to serve them.

Last June, Josh lost the teacher who had made the biggest difference in his life. Josh was in third grade last year but he was reading at a kindergarten level. This teacher found that working 1:1 with Josh helped tremendously, and Josh was reading at a first-grade level at the time she left to go to a public school. Josh quickly regressed when she left. After months of regression or stagnation, Josh has again been improving his reading and is now reading at a mid-first grade level. The change was that the new teacher realized that the 1:1 reading work was necessary for Josh to be able to learn. Many of the teachers and assistant teachers at Josh's school have left. In fact, teacher turnover in 853 schools generally has reached 31%.

Josh has made tremendous gains, but it's clear that he has a long road ahead as he is reading and doing math at a mid first-grade level even though he's in fourth grade chronologically. What I can tell you is that the teachers, counselors, speech therapists, occupational therapists, and physical therapists are all AMAZING. They care so much for Josh and the kids and they go well above and beyond what you would expect because of their commitment to them.

The big problem is that while teachers at both 853 and 4410 schools deal with some of the more challenging students, they are paid between \$20k and \$40k less than their public school counterparts. They have fewer benefits. And they work 12 months instead of the 10 months public school teachers work. It has now become extremely difficult to recruit and retain qualified staff.

It is telling that since 2012, state funding for school districts is up 42%. For 853 schools it's up only 22%, and for 4410 schools, it's up only 8%. We are facing a crisis for our kids most in need.

This two-tier system for publicly funded students in non-public schools has led to a situation where they are being discriminated against by the city and state of New York where the experienced teachers are being snatched up by the public schools, leaving only younger, less experienced teachers for the kids with the most complex learning needs in New York City. I ask each of the legislators and staff to please rectify this funding issue so our kids in 853 and 4410 schools can get the same quality education that our public schools students receive. Our kids' hopes and dreams and their ability to integrate and be productive members in society is dependent on your providing the appropriate funding.

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### COST OF LIVING ADJUSTMENT

Presented by Matt Sturiale  
Chief Executive Officer, Birch Family Services



Good Morning. I am the President and CEO of Birch Family Services - a large not-for-profit multi-service organization that supports individuals with autism and developmental disabilities and their families across New York City.

Today, I am here to speak representing not-for-profit providers across our great state, which are almost exclusively dependent on state funding to meet the needs of the developmental disability community and the workforce that supports them.

**I am asking the NYS Assembly and Senate to ADD TO EACH OF THEIR HOUSE BILLS a 2.9% Cost of Living Adjustment (COLA) to this year's budget. The overall cost for all the human services, not just developmental disabilities, would be \$140 million (State share).**

Let me try to highlight some of the reasons why this is a critical item to support.

1. **Not-for-profit organizations are linchpins of many NY communities providing critical services and resources to individuals and families.** The evolution of supports and services for the developmental disability community since the early 1970s has been based upon a partnership amongst constituents (individuals/families), providers and government. Your support of a 2.9% COLA is essential to sustain and strengthen providers.

About a decade ago, **the NYS Legislature codified a statutory COLA for not-for-profit organizations.** This enabled agencies to increase salaries and address other operational matters such as increased costs associated with rent, utilities, health insurance, liability insurance, workers compensation, pension plan requirements, corporate compliance, facility maintenance, structural improvements and capacity building in such areas as technology. This act was intended to ensure that state- and Medicaid-funded services would receive a COLA each year. Finally, providers had something that we all need – PREDICTABILITY. Predictability enables us to plan, be strategic, efficient and innovative while projecting a sense of stability and security for all our constituents.

2. Well, NOT SO FAST. **In 8 of the last 10 NYS budgets, the COLA was deferred for not-for-profits.** There was a 2.08% increase given in 2010 and a .2% provided in 2017. In light of the growing cost of living, lack of a COLA was a virtual cut, compounded by other cuts, “efficiencies” and unfunded mandates imposed on providers during that period.
3. So, what has been the overall impact of not receiving a COLA?

- Workforce – Recruitment of a quality workforce has been extremely challenging. This limits our ability to support those we currently serve, respond to varying community needs in a timely manner and plan for future needs. We've seen an exodus of talented and committed staff at many levels feeling underappreciated or unrecognized. This leads to significant increases of our overtime and recruitment expenses.
  - Quality - The frequency of turnover in front line positions (direct support professionals, job coaches, frontline managers, teachers, clinicians) makes it difficult to deliver the high-quality services expected by our individuals and families. Many providers have been operating at a 15%-20% vacancy rate over the past two years. Some providers are even higher than that. This challenges our ability to maintain health and safety requirements, facilitate person-centric activities and respond to the emerging needs of individuals and families.
  - Reduction in Services and Program Closures – At a time when the people we support are more included and integrated in their communities, providers are struggling with the ability to maintain innovative and valuable services that keep families together and facilitate independence. Providers are looking very closely at their “bottom lines” in each program and deciding to close those that cannot be self-sufficient.
  - Operating Expenses – The general cost of doing business has not been flat. Providers are constantly looking for ways to streamline processes and reduce costs. This cannot happen without a COLA. For example, in the past five years, our rent increased by 15%; we changed our health insurance carrier three times with increases still rising significantly (almost 6% this year). This makes it difficult for our staff to afford to pay a contribution for dependent coverage. An employee earning \$30,000 and in need of family coverage will pay \$22.96 more per paycheck (\$551 annually).
  - Minimum Wage Increase Has Had a Positive Impact on Our Workforce BUT direct support is not a minimum wage job. – Direct support professionals provide hands-on care that ensures the health and safety, and even the survival, of our very vulnerable individuals. During the last three years, those working in many of our entry level positions (\$11.50-\$12 per hour) have seen their salaries increase by 30% and are now earning \$15 per hour. Our veteran staff with more education and experience, earning slightly more (\$14-\$15 per hour) during that same period have seen their salaries increase by 6.5%, or less than \$1 per hour. Our valued staff are asking, WHAT ABOUT US?
4. I understand that there are a lot of varying interests seeking additional resources from government. How do you choose which constituents to support? I ask you to consider this:
- Not-for-profits are a major employer in many communities.
  - Over the last 10 years, the NYS budget provided a COLA for all state-operated programs; not-for-profits received a mere 2.1% during the same period.
  - Since 2012, the public school district received a 42% increase in state aid, but the non-public special education 4410 preschools and 853 schools received only a tiny fraction of that. I ask again, WHAT ABOUT US?

I ask you to DO THE RIGHT THING AND PASS THE 2.9% COLA IN YOUR ONE HOUSE BILLS and secure the Governor's support.