

Thank you Honorable Aileen Gunther and David Carlucci and members of the Assembly and Senate representing this committee for providing me an opportunity to share. I started my career as a direct support professional in 1994 and found the work to be meaningful, purposeful and important. Today I work as the Senior Vice President of Operations at Heritage Christian Services, an organization that serves thousands and employees over 2500 in the Rochester, Finger Lakes and Buffalo regions of our state. My first real job was when I was 17 years old and I worked at Newark Developmental Center. I was fortunate to have that experience and to see firsthand the strides New York has made in supports and services to people with intellectual and developmental disabilities. We have moved from institutions to community-based programs and are now building a greater portfolio of self-directed and individualized options. We have much to be proud of. And we now move at an unprecedented pace into the undefined world of managed care in hopes of designing a system that delivers even greater outcomes and hopefully at a lower cost.

As many wise, experienced and passion-driven people work tirelessly to find the right path to managed care in a state serving over 130,000 individuals with IDD we become more and more convinced that NY and NY leadership is missing or overlooking the most critical piece. Imagine one of these new large crazy Jenga games all put together standing many feet tall after the work of many people putting it together. Then someone walks over and pulls out the critical piece and it comes tumbling down. In the human service world, and in particular in our world of serving people with IDD, this critical piece is the workforce – the direct support staff. Imagine providing medicine through a g-tube on a daily basis, communicating with people you care about who aren't able to talk, ensuring someone's safety, navigating multiple pieces of unique medical equipment, being counted on to provide personal care and being there for someone on their most challenging days and their best days. This is important and difficult work requiring many skillsets. Without a strong base of good people who want to be doing this work and who can afford to stay we will never continue on our evolved path from institutional care to inclusive communities. **And without this we don't achieve greater equality for people with disabilities.**

A few factors that exacerbate the workforce crisis and are not going away anytime soon: the care gap, record lows in unemployment, the decreasing demographic numbers in NY and the increase in minimum and fast food wages. Add to these major external factors the additional challenges to the daily work environment for direct support staff – including over-regulation and worry that making a mistake will cost you your job.

NY has done an excellent job promoting social justice, women's agenda, equal and civil rights for all and has a keen awareness of the destruction of poverty. And that agenda should carry over to our workforce because the majority of direct support workers are female — in fact 73% are women and 55% are black or Latino. And many live in poverty. We know that 38% of single moms live in poverty in NY and that the starting wage for a DSP is below the poverty line for a single parent.

**You can't say you support women and families rising out of poverty and refuse to pay them a competitive wage for complex work.** They aren't asking for a handout. They are just asking to be paid what they are worth. Right now our state says these hard working direct support staff are worth the least amount of pay set by law...minimum wage. And they aren't even worth the minimum wage set for

fast food workers. What would you pay if it was your loved ones who needed support or care? And would you settle for the minimum? Because if you wouldn't settle for the minimum in care then they shouldn't have to settle for minimum pay.

It is hypocrisy to talk about combating poverty and supporting women's agenda and social justice and pay people more money to pick up our garbage or to flip burgers.

All of this contributes to the care gap. The care gap is the gap between those in need of care or service and the number of people who can provide it. The number of people requiring care increases as people live longer and as medical science keeps improving. Report after report reinforces the workforce crisis we are in as we try to navigate the care gap. See links for additional information:

- 1) ANCOR Report- <https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce%20White%20Paper%20-%20Final%20-%20hyperlinked%20version.pdf>
- 2) Report to the President of US [https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)
- 3) National Core Indicator [https://www.nationalcoreindicators.org/upload/core-indicators/2016\\_Staff\\_Stability\\_Survey\\_Report\\_Final.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/2016_Staff_Stability_Survey_Report_Final.pdf)

[One of the most recent reports suggests we'll see 7.8 million direct care openings from 2016 to 2026.](#) They say that number includes 3.6 million workers who will leave the labor force, 2.8 million people who will leave for a different occupation and 1.4 million [new positions that will be created due to rising demand](#). This reinforces what we feel and experience each day—a workforce that is proud of their dedication to others and the service they provide, but one that is tired, worn out and undervalued. More people are leaving and it is more and more challenging to find good people. Unemployment is at an all-time low and investment in other industries (for example manufacturing and Photonics in Rochester) has left us behind.

NY found a way to invest in the Justice Center, an oversight body charged with eliminating abuse from the supports provided in the different O organizations across the state --- a noble concept. However, in practice, the Justice Center spends an inordinate amount of effort investigating honest mistakes made by good people. This decreases morale among direct support and serves as a deterrent to potential employees who choose to work elsewhere rather than risk making a mistake that could cost them their job and impact their future. Of course we want our service system to be safe and to decrease abuse, but research proves that people are safer when they have meaningful relationships. How does one help to create that when the turnover is at an all-time high and the people doing the work are paid less than a living wage? The Justice Center is not the major challenge here but it certainly is not helping with the workforce crisis.

The regulatory infrastructure has grown and grown over the years---again with very good intent---and now we find ourselves at a point where we spend more time documenting what we are doing than actually doing the work or helping people. We are serving human beings with complex needs and yet we are often forced to document our time in 15-minute increments. I by no means am an expert on

fraud. However, from a lay person's view who is on the front lines of delivering service, all the talk about fraud I believe to be more of a political distraction than a reality. The reality I see is a system dominated by good people trying to make a difference in the lives of others and yet getting little pay or respect. Of course we need strong and solid regulations but that should not be what runs us — our vision to enhance lives and create inclusive communities should be our driving force. When we look through that lens we see plenty of opportunity to devise a regulatory base that is efficient and beneficial and oversight bodies that are focused on true justice for all as opposed to tunnel vision of punishment and fear.

Now as we move into managed care I implore you to consider the workforce as the foundation of this new building. If we have a strong foundation we can build an amazing place where lives can be enhanced and costs controlled. However if the foundation is continuously failing and in need of repair we will exhaust all of our resources or at least a disproportionate amount of our resources there and never get to the amazing work of enhancing lives.

In Governor Cuomo's State of the State he talked about this year being "A Great One." After his public and budgetary support of the Bfair2DirectCare campaign in 2017 we too were looking forward to a great year. Unfortunately we are left discouraged, bewildered and saddened at being left behind. Since 2008 Heritage Christian Services has received on average a 1.3% annual increase for its direct support staff while CPI increase by 1.8% in that same timeframe. If we don't invest in the direct care workforce now New York will be taking steps backward. The quality of care and supports will decline. People will have fewer choices and options, and more people will be served in institutions, which have higher costs and lower outcomes. We are asking NY to invest wisely to improve people's lives and to do so in a fiscally responsible way or we will destroy lives and pay even more for doing so. Gov. Cuomo talks about his commitment to education, health care, MTA and middle class tax cuts. He even discusses a 3.6% increase in health spending and we still get nothing. We are advocating for the Governor to fund a living wage for direct care workers who support New Yorkers with developmental disabilities. For this budget year that would amount to .05% of NY's \$176 billion budget proposal.

We implore you to not only impact this year but to commit to the final years of the of the original six-year plan to provide a living wage for direct care workers. When fully implemented, the living wage for a direct care worker would be roughly \$15.50/hour upstate and \$17.80/hour in NYC. This would show the direct support workforce that they have not been left behind and that there is opportunity to make a living wage and even consider this as a career.

As Gov. Cuomo's father said, "In campaigns it is all about what you say and in government it is all about what you do and the great ones know the difference." I ask you to be GREAT and act in a way to ensure a commitment in this year's budget and a long-term commitment to the hard-working direct support staff and ultimately to the quality of life for New Yorkers living with a disability.