

TESTIMONY SUBMITTAL TO NEW YORK STATE LEGISLATURE, February 9, 2017
JOINT HEARING OF THE SENATE FINANCE AND ASSEMBLY WAYS AND MEANS COMMITTEES,
Re: 2017-2018 Executive Budget for Mental Hygiene

I appreciate the opportunity to submit written testimony regarding the proposed budget for 2017-18 as it pertains to individuals with developmental disabilities. My name is Barbara DeLong. I am a parent of a beautiful daughter, Laura, who turns 25 this March. Laura currently lives at home with us. Laura is severely disabled and relies on us for total care. She has cerebral palsy, is non-verbal, and has swallowing, vision and hearing disabilities. She has no fine motor skills and walks with a very unsteady gait on level indoor surfaces but relies on a wheelchair for long distances or outdoor activities. Laura "functions" at the level of a toddler. My husband and I represent the "aging caregivers". He will be 71 this year and I am not far behind. We worry 24/7 what Laura's future will be when we are no longer able to care for her. We are not alone. There are tens of thousands across NYS that are relying on our legislators to help us. I also serve in a leadership capacity on the DDAWNY Family Committee and SWAN (Statewide Advocacy Network), and hear from families continuously on how the issues below are affecting them. We are in a crisis.

We know that you are all aware of the CRISIS that exists as it relates to our Direct Care Workforce employed by our not for profit providers. It is unconscionable that the Governor has not included any funding to help with funding that is needed to provide a fair wage to these wonderful people who care for the most vulnerable. Our loved ones, by no choice of their own, have lifetime disabilities and they need and deserve quality care. It is their civil right. Direct Support Professionals (DSPs) are our lifeline. They have an enormous responsibility and commitment for very little compensation. The work they do is valued and cherished by the individuals they serve and the families who love them. They care for our loved ones safety, hygiene, toileting, feeding, dressing, wellness, happiness, to mention only a few. They are compassionate and patient; very often they have to "figure out" what our loved ones needs or wants are when there's no spoken language. It is exhausting yet rewarding work. We must provide a fair wage in order to attract and retain quality people to perform this demanding work. Hearts are being broken over and over as individuals watch their DSP's leave for another job because they have to be able to pay their bills. Our loved ones don't understand; they just feel abandoned. Families are trapped in their homes because they cannot find DSP's to help them. We are in a crisis.

There is a huge inequity that exists as it relates to the DSP workforce employed by the State. My understanding is their starting wage is over \$15/hour with full benefits. WHY IS THIS OK? It should be about who's being served, not who's doing the serving. If the Governor's budget supports the wages for state employees at that level, what aren't the people served by not for profits treated the same way? Further, ten years ago there was a significant difference between a "minimum wage" job and that of a Direct Support Professional AS IT SHOULD BE. The wage for a DSP was approximately 50% higher reflecting that the work being performed required significant skills and qualifications and WAS NOT A MINIMUM WAGE POSITION. What has happened? Individuals with disabilities have not "gotten better or easier". In fact, the need is greater than it has ever been. We are in a crisis.

There continues to be a lack of development for residential options for our loved ones. The survey that OPWDD conducted last year revealed that nearly 50% of caregivers were over 60! Further 53% of household have only one caregiver. This is clearly unacceptable. The only way an individual who needs 24/7 care receives "placement" is if they are "categorized" as being in crisis. The placement may not even been in the same region as their family; just a bed.... This is NOT person centered. This is not a process that is focused on the well-being of the individual. There is no venue for having a civilized

transition at the "appropriate time" so the family caregivers can be a part of the transition, providing support and training for all involved. We are in a crisis.

At the same time as the continued lack of residential development, we continue to see respite rates decrease. DOH and OPWDD continue to insist that Respite is a valuable service yet because of the rate rationalization that has occurred; providers cannot continue to offer the service because they are losing money. Families are trapped in their homes; providers cannot afford to offer the service because of the lack of reimbursement. We are in crisis.

In summary, I so appreciate your continued support. Thank you for the opportunity to provide this testimony. Thank you for caring enough to listen and read, to study and reflect, and to take action. I am available to provide additional information or to assist in any way in order to address these critical issues.

Respectfully submitted,

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