Written Testimony for January 31, 2024 Budget Hearings Submitted by Essential Care Visitor.com Founder, Marcella Goheen

The testimony will highlight the need for integral supplemental programming for the vulnerable aging New Yorkers and their caregivers that are residing in long term care community residential facilities statewide, and aging in place in the community - in order to offset the social isolation, address impact of the staffing shortages, support the social determinants portion of an aging person's centered care plan, and, finally - to support a multi-generational education program that is tailored to the next generation workforce to help support the disabled and aging to maintain their highest level of functioning according to their community / state / federal resident rights. All lives are valuable, and this includes our vulnerable New Yorkers who need innovative full care services and support for their needs at this time, as they age in history.

"I am Marcella Goheen, wife of Robert Victor Viteri. Robert is a survivor of Covid-19 living in a long term care facility for nearly eight years. I last testified in July of 2021 for the staffing shortages that plague our long term care communities. As we progress in history, and the staffing shortages remain worse than ever, today I'm here to request financial support for innovative and transformative caregiver programming, in order to serve our 100,000 plus vulnerable New Yorkers, some of whom have no choice but to age in place in a long term care facility, and also, those aging in the community. My husband is a valuable contributor to New York State who served the Board of Education for nearly 30 years. He, and his aging fellows are currently subject to the limitations of the system, considering him a burden. In his own words, "I never want to be a burden". I feel like I'm failing him as a wife. I know he feels this dismissal, though he cannot move, walk or talk.

The long term care facility is a controversial paradigm of over 50 years. While it used to reside in the community in the 60s, with all populations mixed - the institutionalization of the orphan vulnerable segwayed into a medical model in the 70s and 80s. It then graduated to person centered care in the 80s, 90s and then in 2020 Covid-19 took a lot from these communities. But, it also gave a lot, too. It gave us insight and inspiration on how we can do better for our vulnerable who need long term care services. It would be ideal in a perfect world, that we would not have to go into a nursing home. If the center of the services could be at home in the community. But, this is a fantasy, that is not a reality for some New Yorkers, including my husband.

Amidst the work of the Master Plan for aging, the long term care community is always going to be an option for the aging vulnerable. A long term care community is home for some. We do not need to get rid of them to save the dollar, we need to help them get better to save the dollar. The careless climate we live in - is only an indicator of the prioritization of what we value. It does not take much to care. We currently are displaying a belief system that once someone is disabled, or aging - they are not valuable. A smile, a walk, a meal, a music session for 10 minutes goes a long way. Moving a non-mobile resident for 15-20 minutes a day who cannot otherwise move goes a long way. Taking humans outside, to experience fresh air - within the biggest isolation

crisis of our time - goes a long way. All of these kinds of simple services and supports provide a safe aging paradigm that will in the long haul, prevent disease, chronic illness and decline and are what caregivers, whether informal, or formal, currently provide the New Yorker who is disabled and aging.

There is minimal support currently for these caregivers, who are bridging the gap of care happening in New York State in this crisis. In my case, I daily serve my husband with neuro-motor exercises, standing him up with volunteers, and using sensory motor exercises so that he can experience movement. He deserves that - yet, his insurance does not cover it. And the formal caregiving staff do not have time for basic enrichment, yet alone ADL's. In nearly 8 years, he has been to the hospital 2 x, and this includes during Covid-19. What does this augmented system and supportive care by a caregiver show us? That they need to be supported and we need to invest in their contribution, as they present cost prohibitive outcomes.

In my current life, I quit one job of 23 years to serve my husband, and just recently left another, in order to maintain my husband a certain baseline because of the staffing shortage. What I can't understand, is that even with my service to my husband, and amidst a multi-billion dollar industry that thrives off of federal, state and medicare dollars from my husband's disability, that the services and supports that are being delivered on the frontline today remain currently vague, negligent, inconsistent, in some cases - completely non-existent. Yet, the money keeps flowing. What would happen if I was not here? - I ask myself daily. The regulations that are supposed to prevail over this negligence and dismissal, are hardly achieved, and, instead, there is an interplay and focus of litigation of what might more it will take to serve the vulnerable right. For those who represent less than .01 % of the population, yet whose income contributes to over 40 percent of the taxpayers dollars - I ask, not only, how come we can't do better by Robert, but - how can this be? In this back and forth - the family and the vulnerable are the casualties by the very system receiving dollars to serve.

According to the Office of Aging, New York is currently fourth in the nation for population over the age of 60 at 4.6 million, with anticipated growth to 5.3 million in less than ten years. Additionally, 1 in 5 older resident's lives with a disability, and data shows that 70% of individuals over the age of 65 will need some form of long-term care services. We must not wait to get it right, before we deliver the care. This is upside down, and clearly, there is money available toward a compelling and life saving allocation to dignify aging New Yorkers.

When we advocate for baseline services, we, as consumers know we are advocating in an echo chamber, because it is true - the staffing is not there. But, we also highlight today the informal caregivers and family members service to the aging. The families are the bridge and need to be supported. The frontlines of care with this framework for the disabled and aging remain heartbreaking amidst the recent budget propositions.

I refuse to believe that the conflicts of how to serve the aging are because we, as a society, as a strong New York state, do not care. I believe it is because we have not designed or invested in the impactful, sustainable, current systems and support for those who might be interested in the care work to do their job through innovative education, awareness and training. We simply have not prioritized our most valuable, and

believe that we will never age. That it might not happen to us. If there was compassion fatigue pre-pandemic as a baseline from the carers, now, we live amongst a numb, disassociated, traumatized workforce, that is too exhausted and drained from Covid-19 to recalibrate because of the shortage. If you haven't been through an ailing loved one, one wouldn't know. And, I ask the state legislature to put yourself in each of these loved ones' shoes. We are all going to age and experience a disability.

Today I highlight the need for a programmatic overhaul, whereby there is a focused workforce education campaign targeted to the next generation of what care and aging looks like to train and recruit, a creation of internal institutional systems that encompass innovative person centered programmatic supports helping to maintain the vulnerable at their highest level of functioning irregardless of the staff, and a person centered care overhaul to supplement what is currently vacuous chamber of controversy for our aging and their caregiver. We should not live in a world whereby the reason someone is not getting care is because of a staffing crisis, chronic age old litigious positioning over the dollar - while the money still flows. We need to explore what is possible, not keep advocating for what is not possible because of a dollar that is simply not prioritized to the vulnerable. We rely on reimbursement for the budget, but dismiss them for the services. There is a lot of work to do here.

On behalf of those lingering in long term care facilities in New York State, on behalf of Robert, and those aging in the community - I advocate for a complete care overhaul. CARE. Create, Assess, Reframe and Exceed our own expectations of what we might want if we were a vulnerable person needing long term care support. Because, we will be. Please invest in our informal and formal caregivers, because where would we be without them as they hold the finger in the dike. Our aging disabled and vulnerable elderly, are not only New York's most vulnerable, they clearly are our most valuable.