

**Human Services Committee**  
**Workforce Issues Related To Care for People Who Have Disabilities**  
**December 6, 2017**

**Written Statement from Cheryl Dougan**  
**Parent**

Thank you Chairman DiGirolamo, Minority Chairman Cruz, and committee members for your time today.

My name is Cheryl Dougan and I am a resident of Bethlehem, Northampton County. I am honored to speak with you today about Pennsylvania's Direct Support Professional Workforce Crisis. It is affecting our Commonwealth's most vulnerable citizens, including our son, Renzo.

There was a blissful time of life when I was oblivious to this critical and often invisible workforce. No more. My son's life now depends upon Direct Support Professionals, DSPs, every hour of every day.

Our story begins on May 21, 1998, in Bethlehem. It was the first really beautiful day of the spring season. The sky was exceptionally blue and so peaceful. This was a time of life when we were just beginning to feel secure about our future.

My husband, Tony, had just received tenure at Lehigh University the month before and I had begun work on my Master's degree. Our only child, Renzo, was fourteen and already taller than both of us. He gloried in that achievement. We, on the other hand, were proud of his more hard won accomplishments. He was about to graduate tenth in his eighth grade class. He loved playing jazz on his saxophone, but was quickly becoming enamored with the guitar so he could set his poetry to music, like Bob Dylan, one of his idols. He loved playing soccer and Lacrosse. He loved life!

I received a phone call from Renzo's school around 2:30 that afternoon, telling me that he had been rushed to the Emergency Room. I was there within minutes. Our son was unconscious, his body writhing in seizures. Medical personnel surrounded him, one rhythmically pumping air through a ventilation mask held to his face. His clothes were cut away, right through his leather belt, and his chest was wired with electrodes. I clutched his bare feet, the only space left unattended, and struggled to remain calm so they wouldn't throw me out.

I learned that Renzo had suffered a cardiac arrest while undergoing the Presidential Fitness test in gym class. His coach and a police officer had attempted CPR, but not until the EMTs arrived to use an electronic defibrillator did his heart regain its beat. It was too late to prevent a severe anoxic brain injury. Renzo was medevac'd to a Philadelphia hospital where he remained in a coma for nearly one month; his prognosis—likely to remain in a persistent vegetative state.

After nearly three months of hospitalization, we brought Renzo home. Our dining room was transformed with a hospital bed and an array of medical equipment. Our son could no longer walk, talk, eat, or control any of his bodily functions. He couldn't even smile. Neither could we.

Friends and community rallied to see to our every need. They not only raised enough money to build an accessible addition and to buy a van, but they even delivered meals for the next year, allowing us time to construct Renzo's room and adjust to circumstance. Weighed down by immeasurable sorrow, we turned to face the future.

Renzo's care became my full-time job. I sought out and secured the right medical specialists to support Renzo's long-term needs and accompanied him to all appointments. I struggled to make sense of fragmented service systems upon which our son's future would depend. I felt compelled to learn everything I could about special education, health and social services, legal and financial implications and resources, employer based and Medicaid based health insurances, and so on.

It was years before I realized that I had taken on an impossible challenge. Government based systems are inherently subject to radical change as political administrations shift. They will never stabilize or be understood.

I know now that Renzo's well-being does not rest secure amid fluctuating budgets, regulations, program silos and their separate requirements, or a plethora of services requiring endless and often redundant paperwork. Rather, Renzo's life depends upon ethical, compassionate, and competent Direct Support Professionals. They have made all the difference.

Eventually, Renzo regained his smile; it speaks volumes, while his speech remains difficult to understand. His smile does not always tell the truth. In fact, his perpetual smile is part of his brain injury. He can no longer cry. As Renzo continued to heal, he felt the loss of all he had been. Through that beautiful smile he begged, for nearly two years, "Kill me. I can't think." Renzo has survived those years of depression, as have we, largely because of some remarkable DSPs who gave him reason to live.

Renzo's dearest DSP, Jenn O'Brien, has remained committed to him for seventeen years. She began supporting Renzo when her own two children were two and four years old. Her youngest, Keegan, just graduated high school. Already he has a part-time job earning more per hour than his mother, whose salary has remained relatively stagnant.

There has been no increase in pay to reward Jenn for her long tenure, no merit pay for the invaluable work she does, or even a cost of living raise. It's wrong! She is a skilled worker, credentialed in Medication Management, CPR with AED, and to maintain employment, she completes a number of annually required training courses.

Jenn competently assists Renzo at medical, dental, and therapy appointments, monitors his health, and cares for him when he is sick. Jenn supports Renzo to do his part-time job at Martin Guitar, where he has worked for fifteen years. She assists him at Equine Therapy, and in the winter, helps him exercise in a warm water therapy pool. She tends to all of Renzo's personal needs and is the best at trimming his beard, keeping his nails cut, showering, arranging hair cuts, and maintaining his dental hygiene—at 34 years old he's never had a cavity. Jenn helps Renzo shop for his clothes on sale or secures barely worn hand-me-downs; he stays in style!

Jenn and other members of Renzo's team of DSPs take him grocery shopping, cook his meals, do his laundry, and keep his home clean. When needed, they even shovel snow in the winter, so they can get him into his wheelchair accessible van and to work or other appointments on time.

In 2004, Renzo received an Award for Outstanding and Dedicated Service to the Community for his volunteer work at the Easter Seals Preschool Program. He was supported to do that work by a DSP. As a good citizen, Renzo shows up to vote in most elections. The poll workers know him by name. His vote cancelled mine out in a recent primary election; such is his independent nature.

With the help of neighbors and a great team of DSPs, Renzo moved into his own home around the corner from us in 2005. He comes to our house for dinner every Sunday evening. He's sweet, loves my cooking, but he is always happy to get back to his house and to his most cherished DSPs who keep him actively engaged in life.

Somehow, amid the DSPs busy and physically demanding day supporting Renzo's every need, they must carve out time to complete an absurd amount of documentation (in this mom's opinion) that is required by the system. As record keeping moves to electronic verification systems, this profession is growing even more complex. This work has become far more demanding while wages have not only stagnated, but have actually decreased when calculated with the cost of living.

Renzo lost several good DSPs this past year, due to crisis, burnout, or the need to make a living wage. Since fewer quality people are applying to do this demanding work, without commensurate pay, there are a lot more open shifts at Renzo's. Jenn is doing her best to help by doing overtime. She recently she clocked over 80 hours in one week.

Too often, Tony or I are called to cover open shifts and honestly, as we near seventy, it's becoming physically difficult for us to give our son the level of physical support he needs. We collapse in exhaustion and unbearable sadness after spending an eight-hour shift with him.

Not that long ago Renzo had a dynamic team of DSPs, who cared not only about Renzo, but also each other. Joe was a member of that team for seven years. He shares his story in a video you'll view shortly. Jenn is the only remaining member of that team. She is able to continue this job she loves that pays too little only because her husband is able to help support their family needs and provide health insurance.

Renzo is experiencing more bouts of depression. It seems he is having trouble adjusting to so many new people, as they orient to doing his most intimate care. They don't yet know how to assist him at medical visits, support him to do volunteer work, to meet up with friends in community, to workout in the pool, to help him work on walking, talking, or feeding himself. They can't understand his speech patterns, his non-verbal communication. Renzo's life is coming apart at the seams and I feel powerless to help. I'm so tired. This isn't the life we dreamed for our son.

Simply put, people with disabilities need a stable and secure Direct Support Professional workforce in order to survive and take their rightful place as contributing members of

community. The best way to establish system-wide security is to provide DSPs with a living wage.

As a mother, I sincerely thank you for your time and consideration on this issue that is so dear to my heart.