

BETTER CARE BETTER JOBS ACT (S. 2210) *The Voices of Pennsylvania's Families | August 2021*

Shared by Victoria Farrell:

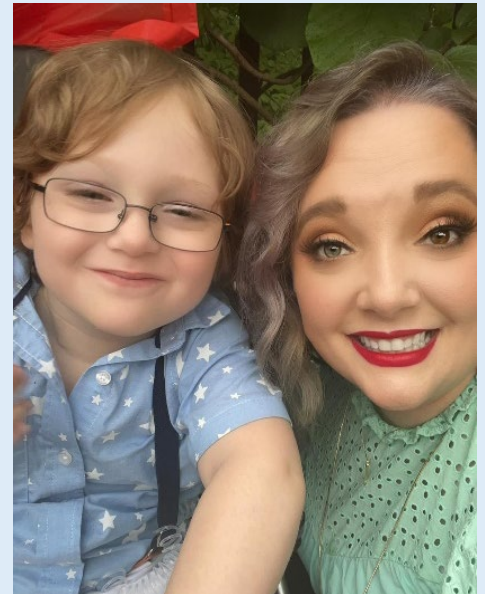
My name is Victoria Farrell and I live in Downingtown, Pennsylvania with my fiancé and my 5 year-old son, Cole. Cole is intelligent, hilarious, curious and full of life and thinks he is the first person in the world to discover Mario, Donkey Kong and Sonic and cannot begin to fathom how Mommy may have played these games as a child because she is "too old." Cole, as of today, would tell you he dreams of being Mario when he grows up, but also a plumber, a Child Life Specialist and a nurse.

The reason he is able to hope and plan for the future is because of home and community-based services.

Cole was born with mitochondrial disease and while he is a bug expert and a budding astronomer, he also faces health challenges every single day. Because of his mitochondrial disease, he has intestinal failure and requires a special IV in his heart called a broviac catheter to deliver the nutrition and hydration he needs to survive. He also has tubes in his stomach and intestines. He lives with epilepsy, severe hypoglycemia, chronic kidney disease, hypogammaglobinemia and muscle weakness, just to name a few.

He requires hospital level care to tend to his medical needs, but thanks to home and community-based services he is able to receive that care at home with us and remain an active part of his community.

Our nurses are the very keystone of our lives. They become family. They provide skilled care for Cole, day and night, including continuous assessments, medical interventions, emergency care, medication administration, seizure care and infection control. The list can go on forever. Our nurses also attend his appointments with his 30 specialists and four therapists, so we are pretty busy traveling to appointments and they are there for all of them. They administer daily therapies, track his progress towards his goals, interact and play with him and help him access his education the way any other 5-year-old would be able to.



Lisa Savage's Story

Lisa Savage left her good union job of 20 years with Verizon where she had good benefits, paid leave and a retirement plan to become a home care worker for her son Brandon after he was shot and left paralyzed. Lisa says that she is her son's keeper. As his home care worker, she is able to provide him an independent life at home, instead of in a nursing home. Lisa said, "As a home care worker, we are essential. Just as our firefighters, nurses, teachers, we are essential because we care for the elderly and we care for people with disabilities at home."



Read more from Lisa in this Philadelphia Inquirer op-ed: [When my son was shot and paralyzed, I learned how broken Pa.'s home care system is](#)

Amy Cichocki's Story:

Amy is a consumer of home and community-based services and a resident of Erie, Pennsylvania. Amy was 15 when her mother became ill and couldn't continue to take care of her. Because her dad was not skilled enough to take over this role, Amy took on the role of finding an outside agency to help in her situation. After much research, Amy was found eligible for Medicaid with the help of Voices for Independence (VFI), who has provided her services since she was 17 years old.

Amy is also now employed as the referral coordinator at VFI, as well as a VFI consumer. Home and community-based services kept Amy out of a nursing home. She passionately believes that in order to ensure the home and community-based services workforce is stable and reliable, we need to make sure they are paid sustainable wages and have access to health care coverage.

Jean Warren's Story:

Jean is a single mother and the caregiver for her 35-year-old adult daughter, Margo, who has Spina Bifida. They are residents of Sharon, Pennsylvania. Jean insists that direct service workers need higher pay, access to skills training and that services need to be expanded so that people with disabilities can remain in their homes. She also thinks it is important to provide oversight of services to ensure high quality. Jean was both a stockbroker and a software salesperson who left her job to care for her daughter, greatly reducing her family income.



Hillary Rothrock's and Craig Benish's Stories:

Hillary Rothrock and Craig Benish live in suburban Harrisburg, Pennsylvania. About three years ago, Hillary moved back home after a divorce and took on the job of providing care for Craig. He has complex disabilities, a result of being born with Duchenne muscular dystrophy, a rare genetic disorder that causes progressive muscle degeneration.

Her role as caregiver is a paid position for which she earns \$12.56 an hour. She also holds a second, part-time job to make ends meet. She and her two daughters live in her mother's home, paying \$650 a month to help with the bills.

Craig Benish wasn't supposed to live beyond 18 years of age. At age three, he wasn't able to walk or run like other children. Most of those who are born with Duchenne muscular dystrophy die in their teens.

Craig lost his ability to walk at 11. He is now 28 years old and has far outlived his doctor's predictions. According to his sister, Hillary, Craig needs 24-hour a day care. The family has home health care workers visiting the house for specialized home and community-based services. His sister provides the everyday care and support needed, every day and every night. Hillary said, "The Better Care, Better Jobs Plan will allow my family to stabilize my brother's care so he can stay home with us instead of living in a nursing facility."

Brenda Young's Story:

Brenda is a 72-year-old senior living happily alone in her trailer in Julian, Pennsylvania. Brenda is legally blind, has COPD, asthma and mobility limitations. Brenda receives 31 hours per week of home and community-based

services through Medicaid. Caregivers help Brenda with everything from household chores to bathing to cooking her meals. Prior to being diagnosed as legally blind, Brenda was only eligible for nine hours per week, which she said did not meet her needs. Brenda said the following, "They do an awful lot for me, they clean for me and they take out the garbage for me. They do a lot that I cannot do. I would sure miss them if I lost them."

Sophia Samuel's Story:

Sophia Samuel of Wilkes-Barre, Pennsylvania faced the difficult choice that millions of Americans across our Nation are sadly forced to confront. She built a successful career as a professor, earning \$80,000 per year. However, her personal success coincided with a decline in her parents' health. Her mother, Elita, and her father, Albert, were both diagnosed with cancer. As they fought cancer, they also battled other chronic conditions, including diabetes and heart disease. On their own at home, they struggled. Sophia helped where and when she could, but her parents needed more hands-on care.

For Sophia, it was important that her parents were able to receive care at home, lest they be sent to a nursing home where they might be separated. She made the difficult decision to leave her job as a professor and accept work with a home care agency, which hired her to provide home and community-based services for her parents. Sophia's salary went from \$80,000 to \$22,000 per year.

Lynn Weidner's Story:

After trying various other jobs, Lynn Weidner landed in health care, where she has found her true passion. She currently provides care full-time for Brandon Kingsmore, who has spastic quadriplegia cerebral palsy. The two first met when Brandon was receiving services at a facility where Lynn worked. Now the two live in an apartment in Allentown, Pennsylvania. Lynn is paid roughly \$12 per hour for her work. Due to her low pay and lack of sufficient benefits, she has accumulated medical debt, forgone medical services she needs and has been unable to take a vacation in years. Providing in-home care is a rewarding job for Lynn, because she knows that it keeps people like Brandon out of a nursing home, allows him to live in his own home and makes his life possible and enjoyable. When describing their daily work, Lynn said that "Everything that an able body person takes for granted, down to the smallest thing like scratching an itch, I do all that. I am his hands."



Brandon Kingsmore's Story:

Brandon has had spastic quadriplegia since birth and requires significant assistance with most activities of daily living. He feels strongly that home and community-based services workers, like Lynn, need to be paid better and provided better training, because they are providing essential services that people like him rely on. He also believes improving compensation can reduce worker turnover, as in the past he has lost caregivers he was close with because they could not afford to continue doing care work due to the low pay. Brandon said that home and community-based services give him a quality of life that he could not have. "We live in a society today that no matter what age you are, if you have a disability and there is nobody to take care of you, you get put in a nursing home."