

MY TESTIMONY IS IN SUPPORT OF SB 580: THE FAMILY CARE ACT

Pennsylvania Senate Labor and Industry Committee

February 3, 2020

I am the Mother of a now 36 year old daughter with disabilities. She continues to reside with us in Southeastern PA.

December 28, 1983, my daughter was born in Grand View Hospital, Sellersville.

At full term, she weighed 2lb., 13 oz. and was immediately rushed to CHOP in a snowstorm. Her diagnosis following genetic testing was chromosomal abnormality with no known syndrome. She was determined "unique." Her disorder manifested in many ways: congenital scoliosis, hemiatrophy, significant hypotonia, seizure disorder, severe gastrointestinal issues, and cognitive and physical deficits.

My daughter spent the first few weeks of her life in the NICU at CHOP before being shipped to our local NICU where she spent another 2 months. My maternity leave ended before I even had a confirmed diagnosis. No extension was available.

I formally resigned from my job to deal with the many surgeries, hospitalizations, and doctor appointments. Upon resignation, I lost access to my tuition reimbursement (working toward a 4 year degree) and had to relinquish my goal of attaining a degree.

My daughter stabilized and she entered school. Like most kiddos she was susceptible to all the colds/ear infections generously shared in these settings, however my daughter required a week to recover and regain the lost weight. To guarantee at least one full-time income, we decided my husband would focus on his career and I would remain home to manage my daughter's medical needs. We spiraled into debt. Despite having health insurance, many costs were not covered. I took weekend evening shifts as a waitress to stem the financial bleed.

When I was able to go back to night school I researched and chose the profession that would allow me to make my own schedule to accommodate team meetings for my daughter, any scheduled and unscheduled surgeries and their associated recovery.

After 15 years I finally entered the workforce full time. Fifteen years of not contributing to our retirement, fifteen years of not paying down debt, fifteen years of just surviving.

The Family Care Act would have allowed me to remain employed in a full time position that provided a steady second income, access to benefits, and a sustainable retirement.

This was my reality, but it should not be the reality of today's workers. I attended the Senate Hearing on SB 580 on January 28 and was heartened by the bipartisan support and thoughtful inquiries of Committee members. The Family Care Act offers financial stability to individual workers, employers, and the economy. It is time to get this important legislation moved out of Committee and put up for a vote. No parent should lie awake at night worrying about their child and paying their mortgage.

Respectfully submitted by:

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