



Proponent Testimony
House Bill 141
House Health Committee
May 7, 2025

Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani and Members of the Committee, thank you for the opportunity to provide testimony in support of House Bill 141 so we can bring prescribed pediatric extended care (PPEC) centers to Ohio. My name is Amelia Auberger, and I am a licensed independent social worker at Cincinnati Children's Hospital. I work in our Complex Care Center, which provides primary care to children with medical complexity. In addition to my role at Cincinnati Children's, I am also the mother of a child with medical complexity and special healthcare needs.

Fifteen years ago, my daughter, Addie, was born at just 23 weeks gestation. She was 11 inches long, weighed 1lb 7oz. and spent the first 119 days of her life in the neonatal intensive care unit (NICU). We learned early in her NICU stay that Addie was considered in a special class of premature babies, known as a "micro-preemie" since she was less than 26 weeks gestation and less than 28 ounces in weight. I remember vividly looking at this tiny human through the foggy plastic of her incubator and my heart aching as she had tubes and wires inserted into her fragile body to sustain life. We could not hold her and were advised to limit touching her as the slightest movement would burn calories that she so desperately needed. The next 100 days were full of many ups and downs. My husband and I experienced a lot of tears, worries, thankfulness and joy throughout this most difficult time in our lives. On day 101 of being in the NICU, my husband and I were elated when we went to greet our daughter at bedside and saw a discharge packet on the counter with her name on it. The next 18 days were filled with preparation to bring our sweet girl home.

While bringing Addie home was one of the most grateful moments that my husband, Carl, and I shared together, it was also one of the scariest as we began to plan for how we would secure safe childcare for a baby who was barely 5lbs and discharging on oxygen and an NG tube inserted through her nose and into her stomach so she could sustain nutrition. Although Addie had skilled needs that would qualify her for private duty nursing in our home, our insurance plan did not offer this benefit, and she did not qualify for Medicaid due to our household being over the income. After learning that there were no childcare centers in our area that were equipped to care for a child with special healthcare needs, we contemplated going down to one vehicle, selling our home and moving into an apartment so one of us could leave the workforce and care for Addie while the other worked to support our family. After much stress, number crunching and contemplating options, we decided to hire a private provider who we trained to provide Addie's medical care in our absence. To make this affordable, we traded in both of our vehicles for less expensive ones and stripped our household budget down to include just the necessities to meet basic needs. While this kept us both working, the cost of this provider was more than our monthly mortgage payment and eventually depleted our savings and caused other financial hardships. We continued to pay the provider out-of-pocket for the next 8 years until Addie finally came up on the waiting list and was granted a waiver through the DODD system that helped offset the cost.

Addie is our first and only child. Due to her extreme prematurity, there were so many unknowns as to how she would develop and what her life would be like. We learned that early intervention was key to these kiddos being able to reach their fullest potential which resulted in us taking her to Occupational,

Physical and Speech therapy 3 times weekly for the next 7 years. While we were fortunate to qualify for FMLA, these appointments used all our sick and vacation time from work and no time for anything else. Had we had the opportunity to enroll our daughter in a PPEC, she would have been able to receive all of her therapies as part of her day in a setting filled with trained medical professionals who could keep her safe and care for her medical needs.

Moving forward in my career, this experience created a passion and determination for me to be an advocate for other parents of children with medical complexities who also have no safe childcare options in Ohio. This resulted in my position as a social work care manager where I can say without hesitation that the lack of options for safe, trained childcare for our patients is the number one factor that creates financial hardships for the families we encounter. This financial strain then creates a domino effect of barriers for the patients that are incredibly hard to navigate and overcome. It is a daily conversation among my fellow social workers and me regarding how we can help families find resources to offset costs so they can pay their bills each month while maintaining some sort of quality of life. While we consider ourselves resourceful and even went as far as to fund raise and started a crisis fund in Complex Care to help these families, it still has not been enough. Food insecurity, mental health concerns and risk of eviction or defaulting on a mortgage are constant worries for families unable to maintain employment due to the medical needs of their child.

To conclude my written testimony in support of HB 141, I hope I have been able to give you at least a glimpse of how the lack of trained childcare providers for children with special healthcare needs impacts not just the child, but the entire family. This problem can be solved by you voting in favor of HB 141 which would allow PPECs to come to Ohio and all children having the opportunity to be included and have safe childcare options equipped to meet their needs. I am truly honored to have been able to present this written testimony to you today and I thank you for your time.

Sincerely,

Amelia M. Auberger, MSW, LISW-S
Social Work Care Manager
Cincinnati Children's Hospital Medical Center
3333 Burnet Avenue
Cincinnati, OH 45229
Phone: 513-636-3000