

Testimony on H.B. 465

by Justin Sodano

End Ohio's Parent Penalty

Pay Family Caregivers National Coalition

4/14/2024

Chairwoman Schmidt, Vice Chair Miller, Ranking Member Denson, and members of the Families and Aging Committee,

Thank you so much for the opportunity to testify in favor of H.B. 465. My name is Justin Sodano and I have been working as a family caregiver for my daughter Mimi, who has an Individual Options waiver, for the past four years. Mimi was born with a rare form of cerebral palsy as well as profound autism and intellectual delay. She lives at home with her mom, two brothers, her beloved golden retriever, and me. When she was born, we didn't know how severe her challenges were going to be. I wish I could say she kept improving and hitting new milestones over time, but that's not true. Every year as she grew, we had to refine our expectations, dropping a few more hopes and dreams by the wayside. She will never go to college. She will never get married. She will never have children. She will never live in her own apartment. She will never hold a job. She will never be able to stay home alone for even a few minutes. She will never be able to talk. She will never be able to go to the bathroom, put on her own clothes, feed herself, or comb her hair. But there is one hope we cannot and will not give up: the hope that she can live safely and happily in our family home.

Years ago, we tried to obtain a Medicaid waiver for Mimi from our county board. We were told by two different employees that waivers are only for people with feeding tubes or breathing tubes. This sounded so specific that we thought it must be true. Like so many other families who didn't know that county boards regularly give out false information to avoid delivering waiver services to children, we gave up and went away. We closed down our family business and called in every favor we could possibly think of in order to keep Mimi with us and pay for the medical care she needed. Without the support of the waiver for which she was eligible, my family had to sacrifice so much. We'd do anything for Mimi. But the breaking point came when our infant son was born prematurely with his own life-threatening health crisis, requiring round-the-clock care. Balancing the needs of two medically fragile children stretched us beyond our limits, both emotionally and physically.

It wasn't until this crisis that we finally challenged the false narrative fed to us by our county board. We discovered that Medicaid waivers were indeed available to children like Mimi, and our guilt for not advocating harder for Mimi was overwhelming. We finally got Mimi the waiver

she should have had years before. We've had some great care workers, and we've also had times when there were no care workers to be found.

I've noticed that people desperate for DSPs will often post an ad on Facebook. Usually, they will try to play up their loved one's positive traits in an effort to attract a care worker. "She's super cute and fun-loving," "He doesn't have any behavior problems and always has a smile," or even classist/racist statements like "We live in a good, safe neighborhood." But what about when the child isn't "cute" and "fun-loving" anymore? What if they have major behavior problems? Everybody wants to work with the social butterfly, huggy, "inspirational" kids with special needs. Nobody wants to work with the kids who kick, punch, scratch, pull hair, or teenagers in diapers.

Four years ago, I became my daughter's paid waiver provider. I did all the same background checks and took all the same trainings as any non-relative would – CPR, First Aid, you name it. Becoming Mimi's paid caregiver was never part of my plan. With an Ivy League business degree and a successful career in quantitative research, I can honestly say I never envisioned myself in this role. But this is what is required to meet the one and only goal I still have left for my daughter – that she not live in an institution.

However, Ohio's new "provider of last resort" rule, which went into effect this year, threatens to upend everything we've fought for. Despite my four years of experience providing high quality, dedicated care, my position as Mimi's preferred caregiver is now under constant threat, with the county board attempting to replace me every four months with fly-by-night employment agencies, some with no website, email address, and out of state phone numbers with no outgoing voicemail message. I've just recently made it through the first brutal round of attempted replacement. One agency my county pushed on my daughter said they'd take the job if the parents would stand by to handle behavioral issues and transportation, and that the parents would have to pay the agency extra money out of pocket to cover the cost of an additional worker.

The county board's disregard for Mimi's safety and well-being is abhorrent. Warren County knows that I am not going to let an unqualified, unreliable stranger with no specialized training or experience care for my daughter. They know this because they have a list of every single injury she has ever suffered while in someone else's care: scratched eye, bitten nose, second scratched eye, cerebral contusion, fracture of occipital bone, subarachnoid hemorrhage, subdural hemorrhage, and the skull fracture that almost killed her. And when she lay there on the floor with a skull fracture and brain bleed, the caregiver in charge couldn't even be bothered to call 911. Despite these horrors, we continue to fight for Mimi's right to safe and loving care in our home.

We need Ohio to support family caregivers the same way Virginia did by considering families as the first resort caregivers and banning these cruel "provider of last resort" policies. This is not a partisan issue. Any family of any political, socio-economic, or cultural background in any of Ohio's 88 counties can have a severely disabled child and end up in the same position as mine,

making heart-wrenching choices and agonizing sacrifices so we can hold on to the one last hope we still have for our kids' futures – keeping them out of institutions.

I urge you to consider the human cost behind ODM's and DODD's waiver policies. By supporting measures like the families-first waiver component of Lauren's Law or even simple legislation mandating updates to OAC 5160-44-32, you can help safeguard the lives of Ohio's most vulnerable citizens.

Thank you for your time and consideration.