

Lauren's Law As Introduced 3-26-24 HB 465

Chairwoman Schmidt, Vice Chair Miller, Ranking Member Denson, and members of the Families and Aging Committee, my name is Jennifer Dietsch and I have a 15-year-old son with severe Cerebral Palsy.

I am testifying today to urge you to pass Lauren's Law. I have friends with severely disabled children all around Ohio and the country. Some of them have amazing caregiver stories but all of them have at least one nightmare story to tell. Passing this law could help save another family from experiencing a nightmare caregiver situation.

A family friend in Ohio cared for her son until she was too elderly and sick with cancer to manage anymore. Caregivers regularly wouldn't show up, leaving both of them in a very vulnerable situation. Her only choice was to place him into a home. He was in his forties living amongst mainly the elderly and he could communicate the lack of care he was receiving but even that didn't help improve his situation. She visited daily and advocated as hard as she could but everyone there just lied about the care he received. If there had been cameras, she could have proved the neglect (which was apparent to anyone with a heart, but no one cared). Cameras change behavior and keep the most vulnerable safe. It's easier to advocate for appropriate care when you can show it has been lacking.

For years, the Ohio disability system has been happy to watch families sink into poverty knowing that well-qualified and dependable caregivers are not available. I was an executive at a state community college until my mother could no longer care for my son during the day. We didn't even have a waiver at that point and no daycare would accept him unless I paid the full fee and provided an aide to care for him while he was there. We lost half of our income the day I quit and didn't qualify for any help. The medical bills piled up, we drained our savings and we would have lost our home if my parents didn't help us. My son did finally receive a SELF waiver, but it would only cover a very part time job IF I could find someone trustworthy and reliable to care for him. As I said before, everyone I know who has used a home caregiver has a nightmare story to tell and I don't want my son subjected to that. He is nonverbal and I would have no way to know he was being ignored or worse, abused, unless it was visible.

No one applied to be his caregiver so I became the paid parent provider of last resort in March. We are finally able to use his waiver and it will give my family a little more financial stability...until May when they'll try again to find a "better" stranger caregiver. I am at the point where I need to have an income so if they find a "better" stranger, I will go get a job at Kroger...until that stranger quits. Then I'll go get a job at another

store...until the next stranger quits.

This does not provide any care or stability for my son or my family. Creating and funding a robust waiver that will ensure families can keep their precious children at home and cared for by those who know and love them best will be life changing for Ohioans.

If it's not possible to do that, following Virginia's lead and not including the provider of last resort provision is a great place to start. There are a lot of safeguards built into the system. We all know not every parent is a great caregiver. But not all parent caregivers are bad either. My child has blossomed under my care and doctors can't explain why he presents the way he does with the severe disability he has. He is full care in all aspects of life also but does many things he shouldn't. He is seen by teachers, therapists and doctors all the time who know how well loved and cared for he is. I should not be considered the provider of last resort over a stranger who decided yesterday to do home care and has never met someone with cerebral palsy much less cared for them.

Please pass Lauren's Law and remove the provider of last resort provision so that families in Ohio can care for their children without sinking to the point where they need other public supports to survive.

Thank you for your time.

Jennifer Dietsch