

Testimony on H.B. 465

by Stephanie Murray

Parent and Disability Advocate

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 Stephanie Murray and I have been working as a family caregiver for my son for the last two years under Appendix K, which allowed for parents like myself and other family caregivers to be paid to care for our disabled loved ones in their own homes. Prior to being his paid caregiver, I had to fight to get him onto an Individual Options Waiver from a Level One Waiver because his needs had greatly increased due to new medical complexities. I had to fight to get onto the Paid Family Caregiver Program under Appendix K as my county board did not tell me about its existence and still tried to deny its existence in the fall of 2022, and I'm not the only family caregiver who experienced such a denial.

When my son was much younger, I tried hiring an in-home health aid several times. They often called off or were very late for their shift, and they frequently smelled like marijuana. As this was before medical marijuana was legal, it was disturbing to me that these people were clearly not drug tested properly before coming into my home to provide services to my disabled minor child. I decided that if this is what in-home care looked like, I was going to do everything in my power to stay home and take care of my son myself. For my son's entire life, I've pretty much been his sole caregiver, with the exception of his father, and his grandfather who have helped in the capacity that they are able.

Appendix K was incredible in that it allowed me to be recognized for all of the hard work that I do with my son daily. It allowed me to stay home with him and be able to help provide financial support to my family. It allowed me to buy him things he needed, like extra supplies for school, special adaptive equipment, and whatever else he needed for his in-home instruction through his district that he does because of his current medical complications. I didn't have to wait on funding through the county board, his Medicaid waiver, or his medical insurance. All of which can take months or longer and still be denied, requiring a lengthy appeal process. I was able to just purchase the things that he needed to maintain a healthy, safe, fulfilled lifestyle. Such as a swing for our porch, an adaptive tricycle, a better protective carrying case for his AAC device, adaptive shoes since he can't tie up laces, and much more.

My son needs a lot of help throughout his day, and he also needs constant supervision because of his medical complications that can cause injury or be life-threatening. It wasn't until I started pulling some other advocates in to help me advocate for others earlier this year and once I

started the provider search to replace myself as my son's caregiver as I am required under OAC 5160-44-32, that I learned how truly atrocious our care worker situation is in our state. County Boards are in constant noncompliance with OAC 5123, and it's a fight for anyone to get waiver services. The list of providers that I was sent to interview had repeated compliance problems for several years in a row; which included not doing background checks on care workers before they were sent into people's homes to provide services.

I found out that the compliance reports available on the DODD website are just summaries and don't show the full breadth of the agency's issues. I also found that several of the agencies that I was sent to interview have substantiated MUIs against them and their workers for abuse and neglect that have not been addressed. Other family caregivers told me about their experience with them, and that the workers who were found substantiated under those agencies are still providing care and not on the Abuser Registry. As such, I was also informed that the Abuser Registry is almost two years behind in reporting. DODD stopped reporting on the number of MUIs across the state back in 2015, and this all begs the question as to why.

Lauren's story is not a one-off situation concerning what can happen at the hands of care workers and the lack of oversight as to what is done about it to ensure that it doesn't happen again to someone else. It is the norm in our system, as it stands now. I have many substantiated stories that would make your head spin with questions as to how this is allowed to occur on such a frequent basis in our state. I decided to remove myself from the Family Caregiver Program because I cannot in good conscience allow anyone else but trusted family to care for my disabled son right now, and I've been told by DODD that ultimately it's up to my county board to decide what provider is considered "willing and able".

Under OAC 5160-44-32, if I exercise my right, and my son's right, to free choice of provider and say no to these agencies with compliance issues and substantiated MUIs, I can be kicked off the family caregiver program altogether, and I have no right to appeal this decision as section (J) states; A decision by ODM, ODA, DODD, or their designee related to whether someone qualifies under this rule to serve as a provider or a direct care worker for an individual is not subject to notice and appeal rights under division 5101:6 of the Administrative Code. I have gone back to providing qualified care for my son for free to protect his rights and his health and safety. We need Ohio to support family caregivers like Virginia did, by banning the "provider of last resort" policy that is not required or even suggested in guidance by CMS. Anyone can become disabled at any time, and anyone can have a disabled child, and as such, this is a nonpartisan issue. I urge you to consider the human rights of our most vulnerable population and the real cost behind ODM and DODD's waiver policies. By supporting Lauren's Law or even simple legislation mandating updates to OAC 5160-44-32, you can help start the process of turning this sad state of affairs around for our most vulnerable population in Ohio.

Thank you for your time and consideration in these matters.

Sincerely,

Stephanie Murray

If you have further questions, I can be reached at:

stephmurrayphoto@gmail.com