

Breaking Silences Advocacy Committee

April 22, 2024

Interested Party Testimony for House Bill 465

Thank you Chairwoman Schmidt, Vice Chair Miller, Ranking Member Denson, and members of the House Families & Aging Committee for the opportunity to submit written testimony on House Bill 465 otherwise known as Lauren's Law.

As advocates, many of us were thrilled when we heard about Lauren's Law and what the bill hopes to accomplish – expanding the right to record in care facilities beyond just nursing homes, as well as creating a waiver component geared towards supporting Ohio families. Both of these aspects are integral to individuals with disabilities. We were especially interested in the latter portion of the bill, in light of all the recent restrictions placed on family caregivers that went into effect this past January. The restrictions on family providers have resulted in devastating consequences for many individuals served under Home and Community Based Services (HCBS) waivers and their families.

Several advocates previously had the opportunity to testify in front of Representative Carruthers and the House Finance Subcommittee on Health and Human Services that she chairs, regarding the Direct Care Workforce Crisis – and its impact on providers and those who receive HCBS services – during the last budget season. We want to thank Representative Carruthers for hearing the needs of the disability community, their family members, providers, and disability-centered organizations and for spearheading this effort.

This proposed bill does a lot of great things from encouraging – rather than discouraging – family providers, to paying them 90% of what an Intermediate Care Facility (ICF) would be paid to provide that same care, to removing the current age restriction of the waiver recipient that significantly impacts the parents' ability to provide their child care, and it even states that participation in this family provider 'waiver component' cannot be denied to an individual without first proving that residing in the community would be an unsafe option for the said individual. All of these aspects are so important. However, we do feel that there is one major oversight.

Where, the bill falls short is that it is only geared towards those with developmental disabilities who are served under The Department of Developmental Disability (DODD) waivers. This begs the question, what about the rest of us? What about those of us with developmental disabilities, or other disabilities, that are served under other types of waivers? Do we not deserve access to the same services as our peers? We believe that we do. It is important to note that we do not get to choose which waiver we're served by: DODD, Medicaid or Aging waivers. For that reason, we think that this particular waiver would exclude others from receiving the same services. These requirements need to be built into existing waivers, or this waiver needs to include everyone eligible for HCBS services. As stated previously, this bill does a lot of good, and we believe that good should be solidified for all who are served under HCBS waivers. We would like to see this expanded to ensure equality for all.

The new caregiver rule, put in place by Medicaid, that has created so many hurtles and restrictions for family providers, affects ALL of us. It affects those with minor children more than others, but it does impact us all. The law passed in January of 2024, forces family providers to work for agencies preventing them from being independent providers. It limits some family providers to 40 hours a week, regardless of how much care their child needs and has been awarded. It makes family members the provider of last resort, meaning if you can find any warm body to take your case – whether they have the appropriate experience for the case at hand or not – you must allow that provider to provide the care. Even when there is a highly qualified family member, who is well attuned to the needs of the individual, and they want that family member to provide them the care they need. The individual should have the ultimate choice to choose who their provider is, including the option to have any family provider that they deem appropriate. No legislation should contain any language to prioritize one type of caregiver over another.

After all, how would you prove that any willing provider is actually more qualified and better able to meet the needs of the individual than a family member could? Would you feel safer with a stranger providing you care for your disability or rare disease(s) that the provider knows absolutely nothing about? Would you feel safer with a stranger that has no experience operating certain equipment that you need to function or live? Often times, there will be a trail of providers rotating in and out from one agency, or simply due to the frequent turnover in this field from the ongoing provider crisis. That adds a lot of stress for the care recipient.

The January rule also created the “extraordinary care instrument” to determine if a minor child is essentially “disabled enough” to have access to family caregivers, rather than non-family providers. Waiver recipients and families already have to jump through hoops to receive a waiver in the first place. They have already had to prove their level of need and disability; they shouldn’t have to do it all over again just to be allowed to have family providers. Usually, family members are going to be more concerned for, and more attentive to, their loved ones who require care, than a stranger would be. Lauren’s story is, devastatingly, a prime example of that. Lauren DOES deserve better. Everyone experiencing abuse and these complex issues around needing care, inside and outside of institutions, deserve better.

Though we are advocating for less restrictions and an easier process for family caregivers, we realize that there needs to be protocols and safety measures in place to protect from a family member who would not have the individual’s best interest in mind. We want to ensure that anyone working for an individual, including family members, would be monitored to ensure the safety of the individual.

We are happy to see that the right to record is being upheld and expanded to other types of care facilities, including ICFs. This is a very important component of this bill, and it is well explained and spelled-out. Lauren’s story of the abuse and horror she has faced at the hands of those who were supposed to provide her care, is sadly one of many. It is essential to take any steps that we can to prevent abuse to the individuals needing care moving forward. We would like to see the right to record expanded to all types of care facilities and all situations where care is being provided to individuals with disabilities, as we are more prone to being on the receiving end of abuse. In fact, “70% of disabled people experience some form of abuse and are 3 times more likely to be sexually assaulted.” It is our hope that the ability to record in care-settings will keep the provider accountable for the services they are responsible to provide.

We want to again thank Representative Carruthers for this advancement in HCBS services and thank you for to the committee for the opportunity to submit written testimony on House Bill 465.

Respectfully Submitted April 22, 2024

Breaking Silences Advocacy Committee

Maria Matzik – Chair and Disability Advocate

maria.matzik@acils.com

Sources:

1. Sanctuary for Families (2022). The Links Between Disability & Domestic Violence. Retrieved from <https://sanctuaryforfamilies.org/disability-domestic-violence/>