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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 testify on House Bill 465 otherwise known as Lauren's Law. My name is Jennifer Kucera and I am the Chair of The Ohio Olmstead Task Force (OOTF). OOTF is a statewide grassroots coalition of Ohioans with disabilities of all ages, family members, advocates and organizations advocating for the right to live, work and participate in their communities. Formed in 2002, OOTF supports the Supreme Court decision that held that unnecessary institutionalization is discrimination against people with disabilities.

OOTF believes that people with disabilities must live in a safe, secure, and appropriate setting that meets their needs. We believe in the least restrictive environment as possible. This least restrictive environment often means residing within the community, and there are several settings which make this possible. For example, a person may reside with family, group homes, supported housing, living independently in their own apartment, and many other options.

The person with the disability should always be at the center in making any decision over their life unless the person has a guardian. In that case the guardian obviously makes the choices for the individual but still should consult with the individual as much as possible.

In some situations, living with parents or family members is the best solution, no matter the age of the person with the disability. In the current system, the only options for family members to take care of their family member with a disability, in the Developmental Disability (DD) level of care waivers is either shared living or utilizing the extraordinary care document.

Even with these two options, there are many complications and stipulations. The system in its entirety must be examined. With all the rules and regulations in place, it is difficult to get direct care providers to care for a person with a disability whether they are family members, independent providers or agency providers. We have a care crisis in Ohio and across our nation!

Even with the new budget, and the provider increases, direct care providers are still not paid what they are worth, are not provided any benefits, cannot unionize and in many situations cannot work overtime. OOTF agrees with this bill, to the degree that family providers, along with all direct care providers, should receive more pay for caring for people with disabilities. But this must happen in all of Ohio's waivers including, DD level of care waivers and nursing home level of care waivers. OOTF believes in parity.

With that being said, we cannot fully support HB 465 and bring several issues to your attention.

Ohio must ensure that the individuals impacted by this bill are protected in their communities.

As we stated earlier, people with disabilities deserve to live in the setting most appropriate to their needs without fear of abuse, neglect, or harm. We recognize that some families choose for their loved ones to live in Intermediate Care Facilities (ICFs). Even though we don't support this bill fully, we are completely supportive of advanced monitoring, with resident consent, so as to assist with mitigating harm and/or potential harm. We feel that advanced monitoring should be allowable in all congregate settings, including nursing homes, ICFs and group homes.

There must be more provisions and protections of individuals with developmental disabilities in this bill. We are concerned about the process on how the individual with the disability would be removed from the ICF and moved into the community. Currently the bill does not state that the individual must live with the parent(s) receiving the additional funds each month. This could cause misappropriation of the funds, especially since there are no reporting measures spelled out in this bill. The bill also does not state how long the individual would need to remain in the facility before waiver approval.

There is no provision in the bill, for family who is currently taking care of someone in their home. They may choose to place their loved one in an ICF, wait for them to get on this new waiver provision, and then bring them back home in order to receive more money than the current system allows. Would you fault a family member from taking these drastic steps to ensure they could receive more funds to care for their loved one? Unfortunately, moving people with Intellectual/Developmental Disabilities (I/DD) back and forth could cause a great deal of trauma to the individual being moved. To guard against this all families should be paid the same rate for taking care of their children (and adults) who have high levels of care needs.

Ohio must ensure that there is a reporting mechanism with the distribution of funds.

It is unclear how the monthly payments awarded to parent(s) would be reported nor the oversight mechanism of the funds. We have the following questions regarding the payments:

- How are the parent(s)/family members held accountable for the funds to pay for home and community-based services?
- How do we know that the funds are spent in their entirety? What happens if the funds are not spent in their entirety?
- Where would the funding to support these payments come from?
- How will Ohio ensure with these new components that there will not be any Medicaid fraud?

There must be an accountability and reporting mechanism for the funding to ensure that individuals are receiving proper care in their communities. Due to the laxity of the language in the bill and no accounting for how the money is used, we have significant concerns that individuals with disabilities could be at risk of being used for someone else to receive the funding or of the family not using the funds properly.

Additionally, there must be a yearly review process, similar to the other waivers. It is not uncommon to hear of abuse by family members of individuals with disabilities. It is important to ensure the safety of individuals regardless of their living setting along with the caregivers. The language in this bill does not

state third-party providers have to be approved by Medicaid. All care providers working with individuals with disabilities must go through the proper Medicaid approval process.

Ohio should ensure that there is equity among all waiver recipients regardless of disability.

The language in the bill is confusing pertaining to the new waiver. In the beginning language, the bill states that Ohio would create a new waiver specific to individuals who would qualify under the legislation. The language also states that there would be a waiver component. We recommend clarifying if the stipulations in the legislation would be part of an existing waiver as a waiver component or a new waiver altogether.

We would like to advocate that these services be added to all existing waivers, including DD level of care waivers and nursing home level of care waivers. Not everyone with a developmental disability is on an DD level of care waiver. OOTF believes that this would cause disparity across waivers. Family caregivers and non-family caregivers would still be paid different amounts depending on the particular waiver that the person with I/DD utilizes. Also, for those that acquire disability after the age of 22 or those with high care needs due to disability (non-I/DD), they would receive lower rates of pay for their caregivers. Lower rates of pay would further exacerbate Ohio's care provider crisis. Care providers will go where they are paid more. We need parity across all systems and all waivers so not as to cause unintended consequences.

In summary, Ohio must provide equitable services for all people with disabilities, increase funding availability across all waiver systems for home and community-based services, and require reporting and oversight requirements for the funding.

We appreciate the intent of this legislation and agree that residents of ICFs should be allowed to have cameras in their room; however, we cannot agree with monthly payments without oversight, accountability and reporting. We also feel that change should occur in all waivers to increase parity. Thank you for the opportunity to provide testimony on HB 465, please let me know if you have any additional questions or concerns.

Sincerely,

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