

April 22, 2024

Honorable Chair Schmidt and members of the House Families and Aging Committee,

Thank you for this opportunity to share testimony today, in reference to H.B. 465

I want to start by stating, I whole heartily believe in the necessity of family caregivers and the importance of people with disabilities (even the ones with intensive care needs) being able to stay in their own homes and communities. I believe that the safety of people with disabilities is critical. I am the mother of 5 children. My oldest daughter has significant disabilities and would meet level of care for an Intermediate Care Facility (ICF). It is important to me that she has the opportunity to live in her community and with her family, while remaining safe and protected.

My testimony is not to counter any of the points that exist within this bill, but to highlight the items within our system that could be used to reach a similar outcome without the need of new rules or policies.

I believe that families and people with disabilities should have greater control of their Medicaid funds. Greater budget authority, authority to choose who cares for them, and the ability to schedule these people as needed. This model exists in our system as Participant-Directed Homemaker/Personal Care (OAC 5123-9-32). This model is known as Self-Direction and is a way of obtaining this greater control. Self-Direction is not new to the state of Ohio, many advocates have worked tirelessly to see self-direction become a greater option within the Medicaid waivers that currently exist within Ohio.

With the ending of Appendix K and the rule changes implemented, there are avenues that are available to families, that will ensure they are able to provide the care, protection, and control, that this bill seeks to establish.

In this bill it states that the Ohio Department of Developmental Disabilities would be responsible for implementing rules around families receiving 90% of the daily rate currently paid to ICF's. The Ohio Department of Disabilities already has multiple options for people to remain in Home and Community Based Services. The time it would take to create new rules and policies, would be extensive and prolong the process of people remaining in their homes with caregivers of their choosing.

With any use of Medicaid dollars, there is oversight that is required. By using Participant-Directed Homemaker Personal Care these oversight needs would be met. People with disabilities and their families would be able to negotiate a wage for their staff and they would have the ability to pay up to (as July 1, 2024) \$27.32 per hour.

This, already existing option, is a viable solution to the need and desire of family care and care from people of a person's choosing. However, it could be a more viable option with the amending of certain aspects of this rule. Currently, to use this Home and Community based service through the Ohio Department of Developmental Disability, the care giver chosen must go through the process of becoming a Certified Independent Provider through the department. While this a reasonable and needed step for caregivers who wish to make a career out of providing support to multiple people with disabilities, it is a lengthy and complicated process for caregivers who are working through Participant-Directed Homemaker/Personal Care.

Caregivers providing support to people with disabilities who utilize the Participant-Directed model, are people who have been identified and chosen by the person with disabilities and their families. They are approached by the person with disabilities or their family to support them. These are not strangers right off the street but are people with whom a relationship already exist—people with whom trust already exists. This would not mean that there are no checks and balances, but that the additional process of Independent Provider Certification would not be necessary. A third party, Financial Management Service, would be responsible to run the background checks, and the person with the disability and/or their family would facilitate the training needed to best support them. Many states utilize this process with great success and the Ohio Department of Medicaid is currently reviewing their policies to eliminate the need for any Independent Provider training.

This option is cost effective, has been proven to provide more satisfaction, and additionally greater results. H.B. 465 is correct in its assertion that people with disabilities and their families should be trusted, supported, and can choose caregivers they know and trust. The Ohio Department of Developmental Disabilities already has a way of doing this that is often underutilized.

Additionally, I would propose opening self-direction to include nursing supports for those who require them. In my own experience, I have found nurses in my community that would (due to the relationships I have been able to develop) be willing to work with my child. With no option to self-direct these services, they would have to work for an agency or would be required to also go through an independent provider process.

People with disabilities and their families, deserve the right to know that the care they receive is of their choosing and within their control. Greater voice, choice, and control are integral parts of Home and Community Based Services. Family caregivers are a critical component of this being achievable. The disabled community needs family caregivers to combat a staffing crisis that already exists. We must support people with disabilities and their families. We must also ensure the safety of these community members as well.

Thank you for your time and attention to this matter.

Respectively,

Sarah Davies

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Parent of a child with Disability