

To Committee Chair Huffman and members of the Senate Health Committee:

My name is Susan Koller. I live in Cincinnati and am a member of the Ohio Home and Community Based Services Coalition (OHCBS). Thank you for allowing me to submit this written testimony in support of OHCBS's goal of maintaining and expanding home and community-based services (HCBS) in the biennium budget. I am a proud member of the coalition and am passionate about its work to increase funding for HCBS because the availability and quality of HCBS directly impacts my life.

I have cerebral palsy and need help with all my activities of daily living. In April 2018, my life got turned upside down when I moved out of my mom's house in Dayton and into a long-term care facility/nursing home in Cincinnati. My move was necessitated by a lack of home and community-based services – specifically the current shortage of direct care workers (DCWs).

Until my move, I always lived in the community either with my family or at college. I was fortunate that for most of my life my parents did all my care. However for 11 years before my move. I had DCWs from numerous home healthcare agencies helping my mom with my personal care. This enabled my mom to work as a teacher and me to work both in the community and from home. This system was not perfect. There was a lot of turnover and call offs amongst the DCWs, but my mom and I made it work. It was getting progressively harder to find DCWs, and in January 2018 I had no DCWs.

I never planned on living in a long-term care facility. Before I moved, I had my name down for an accessible apartment and was going to try living by myself. Since there were no DCWs available, this was impossible. In fact if I moved out on my own I would need more help from DCWs because they would have to do all the household chores that my mom did along with all my care.

I chose to live in a facility for several reasons. My mom is older and can no longer care for me 24/7. I was also worried about what would happen to me if mom had a medical emergency. I would have no one to care for me. I also thought by moving to a facility I would avoid the stress of the DCW shortage.

However when I moved to the facility, I learned that facilities are dealing with the DCW shortage as well. Facilities deal with many call offs and a high turnover rate – just like in the community. These two issues sometimes lead to long waits for care, residents only receiving basic care, and residents constantly getting used to new staff.

Making matters worse is the fact that along with dealing with issues I dealt with receiving care when I was living in the community, I now deal with issues that are unique to facility living as well. I find facility life somewhat restrictive. By far, the worst aspects of facility living for me are not having the individualized care I received at home and not having as much say in how I want my care performed. I really miss the freedom and self-determination I had in the community!

That is why I am starting the process of trying to live in the community again. However, I cannot realize this dream unless I find both high quality DCWs and accessible housing. Disabled Ohioans, like myself, and older Ohioans have the right to choose where we want to live. However in order to live where we want to, we must have access to the services and DCWs we need.

Beyond the fact that everyone should have the right to live where they want to, there are two other important reasons to ensure all Ohioans have access to quality HCBS services. First, it costs state governments a lot more to have Ohioans with disabilities and older Ohioans living in facilities than it does to have these groups living out in the community. Second, the coronavirus pandemic highlighted the risks faced by individuals living in congregate settings.

Thank you again for allowing me to submit written testimony that highlights the importance of providing more funding for HCBS in the upcoming biennium budget by sharing my own personal story. I cannot urge you and your fellow senators strongly enough to incorporate OHCBS's goals into the upcoming biennium budget. If you are interested, I would love to have a more detailed conversation with any of you about the importance of HCBS, which impacts the lives of so many Ohioans.

Sincerely,

Susan Koller

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