Jennifer Kucera

House Finance Subcommittee on Health and Human Services

Interested Party Testimony, HB 33

Chairperson Carruthers, Ranking Member Liston, and members of the House Finance Subcommittee on Health and Human Services, thank you for the opportunity to provide testimony on HB 33.

My name is Jennifer Kucera. I am the chair of the Ohio Olmstead Task Force's Direct Care Workforce Crisis work group. I have 53 years lived experience as a person with a developmental disability namely Spinal Muscular Atrophy. I currently have a Medicaid Home and Community based waiver through the Ohio MyCare delivery system instead of a Department of Developmental Disabilities waiver. I am speaking here today on behalf of people with disabilities that live in the state of Ohio and have access to home and community based services.

My main message today is to show that care providers are critical to the health and independence of those living with disabilities.

In general our caregivers help us, people with disabilities, live with greater dignity and independence; and lead more fulfilling and enriching lives

Caregivers help level the playing field so to speak and give people with disabilities an opportunity to focus their lives on other things besides just survival.

Caregivers assist with activities of daily living (ADLs) that vary from person to person. They help us do the things that non-disabled people take for granted and don't have to spend a lot of time thinking about.

When people with disabilities don't have adequate care they have to do things like sleep in their wheelchairs or stay in bed, go without eating, bathing, and must endure improper toileting. The prolonged effects of going without one's basic needs or activities of daily living (ADLs) being met will begin to effect the health of the individual both physically and mentally. Urinary Tract Infections can occur, pressure ulcers and other wounds can develop, and malnutrition are just some examples but which in all cases can lead to expensive hospitalizations and in extremes, death. Mentally, inadequate care results in anxiety, depression, low self-worth and feelings of learned helplessness. These mental issues do inflict trauma but can also lead to hospitalizations and if it goes on long-term can also cause death.

In an institution people with disabilities do not typically receive one-on-one care. Care providers in Institutions have to serve many people during a single work shift. They cannot be there every time someone's nose itches to help them scratch it like my own in-home caregiver can. When a carer enters someone’s home, they are there to assist them and no one else. This is focused care which in turn leads to healthier outcomes. Yes, many caregivers have multiple clients but not at the same ratio as caregivers employed in institutional settings.

I want to share a bit of my personal narrative to illuminate the points I have made.

I was a math teacher at 3 local colleges for 25 years. The reason that I got let go from those jobs? My caregiver realized he didn’t want to care for me anymore. This didn’t happen all at once but slowly. With his increasing lack of care my health began rapidly declining and I ended up with numerous Emergency Department visits and lengthy hospitalizations. Until ultimately, it led to a nursing home stay, which finally ended my ties to that particular caregiver. While in the Nursing Home some aspects of my care, did get better. Wounds healed, albeit slowly. I was eating and drinking again and getting sleep in a bed. But, due to inactivity of some days not being able to get out of bed, due to low staffing and being unable to have a productive life, like a job, going places within the community, any activity whatsoever I lost the abilities of my right arm. It no longer functions. Also my mental life began to suffer, so I was prescribed a slew of mental medications so I can just cope on a daily basis.

Fast forward to now. I’ve been living in my own apartment for 7 years. Only 1 Emergency room visit and zero hospital stays! I am taking NO psychotropic medication. All because of the right caregivers and correct number of service hours.

I no longer worry about my physical and medical needs being met because my nurse and my 2 caregivers take that burden away from me. It’s a partnership that we all have together. They know me. They can spot things, going on with me before I can. Do they help me with my health? Absolutely, no question! Now, I can focus on my independence.

You would not see me before you today if I had caregivers that did not care. They drive me wherever I want because they know how important my advocacy efforts are to the life of myself and to the people I serve. Advocacy work is what fills my days now as I want to give back all I was given through my life and to help others whose voices are not in the room with us today.

Living on my own, where I can make my own choices on where I live, when I get up in the morning and when I go to bed, the freedom to garden in my front yard, to come and go as I please, visit friends in the community without asking someone’s permission to do so. The freedom to have a job or a career. This is what independence is! Independence gives us power and freedom just like our non-disabled peers.

There are many documented health benefits linked to independence such as: feeling like an individual which increases a person’s self worth, sense of purpose which reduces isolation and feelings of hopelessness and depression. Independence aids in a sense of control which leads to self achievement. These factors all add to a person's mental health, disabled or not. And good mental health can effect physical health in a myriad of ways.

We just want those same chances to create a life as our non-disabled peers do. This is what in-home caregivers can help us do!

As you can see, my story, at the moment, is one of success. A story of what good, stable, consistent caregiving can do. This is occurring with hundreds across the state. But it is a shifting ground, like the tectonic plates, it can change at any time leaving an earthquake in its movement. Literally causing people with disabilities lives to fall through the cracks.

Caregivers do leave all the time for various reasons but one of these reasons we can put a stop to by raising their hourly wages. This can help lower caregiver turnover rates so people with disabilities have a solid plan for care. At this moment in time, if we are lucky enough to have adequate care, we are always wondering will my carer quit today and will I be able to find another. This can break even the strongest of people. Please help us make strides in solidifying our direct care workforce with raising their wage floor and making sure it reaches the hands of the caregivers.

Institutions no matter how hard they try will never truly replace the ability to live in your own home and have a life of your own choosing.

https://vantageaging.org/blog/independence-is-important-for-seniors/

Respectively submitted, March 15, 2023

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