

Testimony of Shelley Jaspering
before the
United States Senate Special Committee on Aging
March 17, 2022

Good morning, Chairman Casey, Ranking Member Scott and Members of the Senate Special Committee on Aging. Thank you for the opportunity to speak today. My name is Shelley Jaspering. I live in Ames, Iowa. I'm 44 years old and work part time as a pricing assistant at Wheatsfield Cooperative. I also love to sew and occasionally sell things at our local farmers market. I have lived in Ames most of my life besides my college years and a couple years in Wisconsin. I returned to Ames in 2003, and I was hired full time at Wheatsfield which also luckily gave me full time benefits including an IRA and short term disability insurance. In 2005 I had an accidental fall which resulted in my quadriplegia. I was not able to return to work until spring of 2006 to work part time in the office because I was no longer able to do the physical labor necessary for my previous job.

Seven years ago I moved into my adapted home built by Habitat for Humanity. My mortgage is more affordable than rent in the college town I live in. I have never been able to afford a new accessible van on my own. My parents assisted me with money to purchase a 2007 accessible van recently, which is my 4th used van. We buy older used vans to keep me out of debt, but they typically require more repairs and upkeep.

I cannot currently save money for emergency situations due to asset limitations which I have to follow in order to keep my Medicaid waiver, which pays for my home care. I use a hometown bank for my checking account and they also manage my mortgage. They allow me to pay on the 10th of the month to ensure my Social Security Disability Insurance check has been deposited, even though this is technically considered late according to the bank mortgage policy. Being in a

smaller community, I believe the bank is more understanding about the fiscal restrictions I have, and they work with me to ensure I do not receive late fees. Because the asset limit rules are complicated and I do not always fully understand them, to be safe I do not have a savings account or credit cards. I turn to my parents for financial assistance when a big bill occurs, but they are in their 70s and will not always be available for this help with paperwork or funds.

There is so much I don't feel confident in my understanding about my fiscal situation. I worry about the details I might miss and might cause me to lose my Medicaid waiver, which is the only way I can contribute to daily life. My SSDI would not be enough to fully pay all of my bills and mortgage, so I am very privileged to be able to work part time. With rising costs of basic needs (food, shelter, and utilities) finances cause stress. For instance, when there is a three paycheck month, it causes me to have to manage and cut my hours so that I don't earn too much money and risk having my benefits cut. This is an inconvenience for my employer to accommodate me which causes tasks at work to go unfinished.

Along with the general cost of living expenses, I have disability needs to pay for as well. I recently found a need for a power wheelchair. Since Medicare would not cover the cost of a power chair at this time, I found a reasonably priced used power chair that I believed would fit my size. I paid out of pocket and couldn't afford a maintenance contract. The arm rests on the chair broke almost immediately because I use them as a way to transfer in and out of the chair. Those arm rests will cost me \$500 to get a set that will accommodate my needs and not break as easily. These additional costs add up fast and Medicare can only help every 5 years with the purchase of a new chair.

If I didn't have the asset limit barriers to saving money, I would be able to purchase more things to help my health and independence without asking for assistance from my parents.

My message here is that disability is expensive and there are barriers to earning enough to cover those expenses.

Most important to me is that I need to manage my finances in such a way that I don't lose my home care support. Without home care, I could not do the basic morning routine that everyone has to do to get up and go to work. Then I would lose my job, my home, and be more dependent on state and federal assistance programs or, even worse, be put into a care facility.

I have always lived with anxiety, after adding a disability into my life 16 years ago, being dependent on others causes more stress. The greatest fear I have is losing my home care because it would take away my life. I'm from a frugal family and was taught to save for emergencies. Unlike my friend who was born with her disability, mine was something that nobody could prepare for. In preparing for her future as a disabled adult, her parents had set up an IRA that would eventually pay for her home care after losing her ability to work as she aged. This preparation kept her from using Medicaid and other assistance programs for many years. For someone like me who acquires a disability later in their working life, it can be difficult to find the financial resources and information to manage this new life.

One thing that would help me is an ABLE account. I urge Congress to pass the ABLE Age Adjustment Act. I can't open an ABLE account because I became disabled at age 28, two years after the age limit. If I could save for the future, for repairs to a van, for repairs to my house, for

repairs to my wheelchair, I wouldn't have to live in fear. The \$2,000 asset limit to keep my disability benefits means that I am stuck financially and will always live on the edge.

In addition, the requirements of Medicaid, Supplemental Security Income, Social Security Disability Insurance, vocational rehabilitation and state programs are overwhelming. We need understandable information about how to manage our benefits and earnings. We need to locate trusted people that we can count on to walk us through the financial stages in life.

Finally, I ask that the monthly earnings limits be increased so that people with disabilities can work as much as they want and need to. I have worked for my current employer for 18 years. In the next few months I'll have an opportunity to get a promotion. For anyone, that would be a good thing but for me, it means anxiety and fear. If I am paid too much, I could lose my benefits and then I couldn't work.

Thank you for your time and consideration on helping the disability and aging community to improve their financial situations. Financial improvements will have many benefits including improving the mental and physical well-being of people with disabilities and our independence.