

Written Testimony of Alene Shaheed  
United States Senate, Special Committee on Aging  
An Economy That Cares: The Importance of Home-Based Services  
March 23, 2022

Chairman Casey, Ranking Member Scott, and the Members of the Committee,

Thank you for the opportunity to share my experience with you today as someone who is enrolled in Medicaid home and community-based services. My name is Alene Shaheed. I am 76 years old and I live in Jacksonville, Florida.

In 2005, I retired after 30 years of doing customer service and started enjoying my retirement traveling, visiting friends, and doing the things I wasn't able to do while I was working. I was also taking care of my nephew during this time up until 2010. In 2013, to have more money, I went back to work as a security guard in a private community. In 2016, I started to experience some mobility issues. I went to the doctor and learned that I had a growth on my spine. It took two surgeries one in February and one in July to ultimately remove the growth. After the second surgery, I was unable to walk and now I use a wheel chair for mobility. I also need assistance with bathing, dressing, housekeeping, some toileting, and meal preparation.

I am enrolled in Florida's Medicaid long-term care waiver and I am approved for 35 hours of help per week. My home health aide allows me to continue to remain living at home and helps me be independent. When given the option, I chose to receive services at home and not go into a restrictive nursing home where they tell you when you can eat, when you have to get up in the morning and go to sleep, or even when you can have visitors. I value my independence and I am capable of living at home with assistance.

I'm very fortunate that I am in the long-term care program in Florida since thousands of people in my situation are on waiting lists because there isn't enough funding for the program. Even being enrolled in the program, I have always experienced gaps in my services when a home care aide didn't show up for various reasons. But there were always workers available. Now and since the pandemic started, the services have been in decline and so has the quality of my life. I am now experiencing lapses in services. While I am approved for help seven days a week for five hours a day, right now I can only find an aide for 20 hours a week. Since January of this year, I have not been able to find an aide to come on Saturdays, Sundays, and Mondays. So I don't have any help for three days until my other aide comes on Tuesday.

This means I am unable to shower for three days. I cannot take out the trash since I can't get in and out of trash room with my wheel chair, which is important for cleanliness. I can only make easy-to-prepare food on my own. A couple weeks ago when I was fixing myself ramen noodles I accidentally tipped over the cup of boiling water on my leg and now have a large burn. Thankfully it did not get infected, but the burn is on my left leg which I use to transfer in and out of bed making it harder for me to do that on my own. I'm also spending more time in my wheelchair because I do not have help, which puts me at risk for pressure sores. I also feel very socially isolated. I live in an apartment complex for seniors. Last weekend, they had a St. Patrick's day pot luck, but I was unable to go because no one was able to help

me get bathed and dressed. Not having the help affects every aspect of my life because the aides are my lifeline to independence. I absolutely do not want to go into a nursing home.

Why is this happening to me and so many thousands of others? It's due to the underfunding of Medicaid and the wages of home care workers are too low. The average pay for aides is \$10 - \$13 an hour. Even before the pandemic, my aides told me they worked two jobs. They would help me during the day and then go work at nursing home at night to take care of themselves and their families. When the pandemic came about, I started to see a decline in the program because the aides were unwilling to put themselves and their families at risk for just \$10 an hour. So now they are going to work for a private agency or they find another job that pays better. The workers are hurt by how little they are paid and I am hurt by how little they are paid. Valuing me means valuing them and valuing them means valuing me. And we all deserve to be valued.

I know that many people are in the same situation as me. These services are our lifeline to remain independent and live with dignity. They must be adequately funded. Thank you again for letting me share my story with you and for having this hearing.