

Testimony of Jeffrey Knight

Consumer representative of the Maryland Money Follows the Person Program

Before Senate Health, Education, Labor, and Pension Committee

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Good Afternoon Senator Harkin, Ranking Member Enzi, and Members of the Committee, I am Jeffrey Knight. I am a participant of a 1915(c), Home and Community-Based Medicaid waiver and the Money Follows the Person Rebalancing Initiative.

I appreciate this opportunity to discuss my experiences living in a nursing facility and how much it means to me to be given the opportunity to return to the community and live in my own home again. Without Maryland's Money Follows the Person program and the new Money Follows the Person program, I would have never had the opportunity to live in my own home again.

First, let me tell you a little history of Maryland's programs. House Bill 752 enacted during the 2002 legislative session, requires social workers in nursing homes to present residents with information about home and community-based services that might help them live in the community. In the 2003 legislative session, lawmakers enacted House Bill 478, the Money Follows the Individual Act. The Act allowed individuals living in nursing facilities to access a 1915(c) waiver, Medicaid home and community-based waivers known as the Older Adults waiver and the Living at Home waiver. The Older Adults waiver was designed to provide Medicaid plus home and community based services for individuals age 50 and older. It also includes transitional services such as the first month's rent, electricity, phone, furniture, household supplies, food, etc. for the first month. The financial eligibility requirements allow individuals who were 300% of Supplemental Security Income level to access the program. The Living at Home waiver is similar but it is for individuals age 21 through 65. Until 2003, anyone could apply for a waiver whether they were in a nursing home or living in the community, but there was a waiting list. In 2003, both of the waiver programs were closed to community applicants because there weren't any slots available. Maryland began a registry for community applicants. The Money Follows the Person Act made it possible for anyone who resided in a nursing facility to receive a waiver without being on a waiting list or the registry. Currently, the registry has 15,000 plus persons on the list waiting for waivers. There is no such list for nursing home residents. Unfortunately, the only way to get a waiver is to live in a facility and be on long term Medicaid for 30 days. The law prohibits the Department of Health and Mental Hygiene from denying an individual access to HCBS waiver services due to a lack of funding for the program.

Maryland is one of 31 states receiving federal funds from the Centers for Medicare and Medicaid for the Money Follows the Person Demonstration program as a result of the Deficit

Reduction Act of 2005. Maryland has developed a Money Follows the Person Demonstration program to rebalance its long term care costs from institutional care to home and community-based services so the money will follow the person into the community. I am a beneficiary of that effort.

I am 49 years of age. I was born and raised in Front Royal, Virginia. I graduated from Warrenton High School. After graduating, I moved to Frederick, MD. I have lived in Frederick County for 31 years. I worked at Fort Detrick as a Custodian for 11 years. I was born with developmental disabilities, Epilepsy and learning disabilities. I have lived on my own and supported myself since I was 18 years of age.

Two years ago, I entered the hospital because of seizures. As a result, I was placed in a nursing facility for 24/7 care because of my inability to walk. My healthcare providers did not feel because of my disability I was able to care for myself. I lived at Citizens Nursing Home, a county owned facility. Citizens Nursing facility is no different from other nursing homes. I had a horrible experience living there. It was depressing being in a place that was mostly older people. I had no one to talk to that I could relate with. I didn't like how I was cared for or how others were cared for. They treated me like a baby. They told me when to eat, sleep, and smoke. I had no time that was private or could be on my own. The small space given to me as a bedroom was small and confining. It was more like a hospital room. You have to share it with someone else. You didn't have your own things. There was no privacy, people in and out of your room, all day and all night. Your personal belongings are not safe. Things like electronics, food, and money are stolen. You hear residents screaming all night long. You have to eat what they prepared for you, not what you wanted to eat. I will never eat chicken again for as long as I live. Just to have a hotdog or a hamburger again was a dream come true. It was not clean. The floors and bathrooms had urine all over them. They didn't give you the therapy to get better. I just sat and stagnated, day after day. I had reached my limit and felt that I had to get away from there. I could not take living there any longer. I was totally disgusted with institutional life. So, I contacted the Maryland Disability Law Center, the local protection and advocacy organization to find out what my options were. I wanted to go home. They worked with me by advocating getting the Living at Home waiver. The Freedom Center also worked with me to help me gain my freedom back.

In October of 2009, I was finally able to leave. Between MDLC and The Freedom Center, my apartment was found and my services were put in place. The Living at Home waiver vendor, The Coordinating Center, helped me develop a plan of service which cost \$48,229.88 for 6 months. This included 16 hours of care for the first three months and 12 hours of care for three more months. After six months, I was able to get the waiver for a year at a time because my attendant care was reduced to 8 hours per day. I don't need as much care now. The cost of my plan of services now is \$25,094.44. It is much more cost effective living in my own apartment and that cost is going down allowing Maryland to save even more dollars as a result of the Money Follows the Person Demonstration program. Because of the Medicaid waiver program and Money Follows the Person, I have my own privacy and freedom to come and go as I please. I am not locked down like I am in a cage. I get to eat what I want to eat. That first hotdog was

the best meal I had ever had. I can eat what I want and when I want to. I am now able to get rehabilitation so I can build my legs up to be able to walk again. I came out of a nursing home using a wheelchair and now, most of the time, I can use just my walker. It is my hope to be able to walk without assistance. My number one goal is to be able to go back to work part time. I can take my medication on my own. I don't have to wait until someone brings it to me. I can visit friends in their homes for the holidays. I can watch TV when I want to. I can watch whatever I want on TV. I really love watching movies either in my bedroom or in my living room. I am able to attend social functions such as picnics and holiday parties. I am, for the last 8 months, enjoying my freedom and being able to control my life in the way I want to. I am at peace. I am becoming a self-advocate and have shown my support by my opposition to Transit budget cuts which would have affected my paratransit services. I will never go back to a nursing home. I will disappear if someone tries to put me back in a nursing home. I am so strong in wanting to live in the community that it was very hard for me while I waited for everything to be put in place so I could leave. I almost left the nursing home against medical advice. I was ready to leave with or without a waiver. I didn't because I didn't want to jeopardize what I needed in services. My life now is what I want it to be. I am happy and I get much better care than I ever did while in the nursing home. My meals are delicious. And, my apartment is clean. I cannot ever imagine being back in a nursing facility. I am relaxing and enjoying life.

Thank you for allowing me to share my experiences with you and I hope that what I have said will help keep these valuable programs in place and allow others to leave nursing homes and gain their freedom as I have.