

Wednesday, February 9, 2022

The Honorable Chair, Shane Pendergrass
House Health and Government Operations Committee
Taylor House Office Building
Annapolis, Maryland 21401

RE: House Bill 80: Home- and Community-Based Services Waiver - Participation and Applications
Position: SUPPORT

My name is Susy Elder Murphy and I am the owner of Debra Levy Eldercare Associates, an Aging Life Care Management company that has been in business for nearly 34 years.

I have worked as a care manager for almost 29 of those 34 years. We are the second oldest care management practice in the state of Maryland, and one of the largest, and employ 15 care managers, most of them full time. Our team is made up of nurses, social workers and gerontologists and we provide support to clients experiencing challenges as a result of aging, disability or both. We serve clients of all ages and currently our oldest client is 102.

Today I am not only testifying as a business owner and full time care manager, but also on behalf of our professional association, the Aging Life Care Association.

We have over 2000 members across the country and over 200 in the Mid-Atlantic region. I served for 2 years as the President of our local chapter and as co-coordinator of our local Metro DC unit for nearly 10 years. I currently also serve on the national board of our association. So the experiences that I will share today are not just my experiences, but typical of the experiences of my colleagues across the state of Maryland. We are all trying to advocate for our clients and their families and to do everything possible so that they can live out their last days with as much dignity and quality of life as possible, even as they face sometimes daunting physical, emotional and medical challenges.

Because I have been in this field for so long, I can actually remember when the Medicaid waiver was first introduced and was successful in getting the waiver for one of my clients, Elly.

- She was German and had married an American GI at the end of WWII and emigrated to the US where she raised their family. After she was widowed, she began to show signs of memory loss and was ultimately diagnosed with Alzheimer's. After her life savings were depleted, she had only her modest social security income to pay for her care. She had already moved to a small group home in Silver Spring, where she was very happy and well cared for. Her daughter was trying to figure out how to keep from having to move her to a skilled nursing facility when the Medicaid waiver was introduced and I helped her apply. Her application was fairly quickly approved and Elly was able to remain in what she considered "her home" until the end of her life.

I was so excited about this success and prepared to guide other families through this process. Little did I know at the time, that that would be the one and only time in more than 28 years working full time as a care manager that I would be able to assist a family in being granted a Medicaid waiver. As the years passed and the waiting list grew, sometimes closing completely to new applications, I stopped even

discussing it as an option with families who had loved ones who were outliving their assets. It seemed cruel to mention something that really wasn't attainable.

About 5 years ago I was contacted by an adult daughter whose mom was in her mid-90's and lived in a group home and had been on the waitlist for a waiver for about 10 years. Miraculously, her number came up and a waiver was made available to them. But by that time, the daughter had developed so many of her own medical issues that she was unable to bring her mom back home to live with her and make use of the waiver to provide care, to supplement what she herself could provide. Instead, her mom went into a skilled nursing facility, the very thing that they had worked so hard to avoid.

Every week we get calls from families wondering what to do because their mom or dad or other family member has already outlived their assets, or is about to, and they are looking for guidance on what the options are. I sometimes mention the "back door" to the Medicaid Waiver, that they can leapfrog over the wait list and qualify for long term care, move to a skilled nursing facility, and then apply for the waiver and move back into the community. The two clients that we assisted most recently with this process were still waiting for paperwork to be completed by the state more than a year after their application had been submitted. In the meantime, they continued to experience decline and the likelihood diminished that their family would be able to provide the care needed to supplement whatever the waiver would provide, and the time that they would have spent with their families was forever lost.

Most recently I worked with 3 families whose stories I think are very compelling and which demonstrate why we need to finally fix the Medicaid waiver system in our state.

1. One family contacted me last year. Their mom was 91 at the time and had been living in an in-law apartment with one of her 6 adult children for the last 20 years, ever since their dad died. However, she now needed assistance with nearly all of her activities of daily living (bathing, toileting, dressing, transferring) and her life savings were nearly exhausted. Those of her children who could, were helping to cover the cost of caregivers to be with her during the day, but her adult son and daughter-in-law were up multiple times at night to help their mom. They were getting some financial support through the VA's Aid and Attendance program, but that didn't begin to cover the cost of her care. Her children had promised their mom that they would not move her to a skilled nursing facility but they couldn't continue as they were. I asked if any of her children lived in any other jurisdictions. In Washington, DC, for instance, an application for long term care Medicaid is presumed to be for support so that the person applying can remain at home. If she had any children in New York state, they might even be able to be paid to provide some care for her through their Medicaid waiver program, if she moved in with them. Ultimately, the family moved their 91 year old mom out of her home of over 20 years to Florida, where the Medicaid rules provided more support for her, without requiring her to move to a skilled nursing facility.
2. Another family that contacted me was looking for ways to provide support for their 67 year old dad who had been diagnosed with PSP, a neurodegenerative disease in the Parkinson's family, although unlike Parkinson's there is no treatment for it, other than anti-depressants to help you cope with your life-limiting diagnosis. Their dad was diagnosed with this terrible illness just before his 65th birthday, and his wife and two adult sons provided care for him until he started needing more help with his activities of daily living—bathing, dressing, transferring and eating. A hallmark of this illness is difficulty swallowing and he required thickened liquids and soft foods to avoid choking incidents or aspiration of his food, which

would lead to pneumonia. The family was East Asian and, in their own home, their parents could remain together and he could continue to eat the foods that were familiar to him, carefully prepared and pureed to a texture that he could safely swallow. His wife was herself not strong enough to assist her 200 lb. husband with his activities of daily living, so they started paying for care, first for a few hours a day, and, by the time they called me and had already spent tens of thousands of dollars on his care, for 10 hours per day. Again, these sons were willing to care for their dad in the evening and overnight. But they needed someone to help out during the day so that they could continue to work and pay for the mortgage on the home they all shared. A Medicaid waiver would have made the difference between keeping their parents together or splitting them apart for the last years of their dad's life. Between being able to watch his grandchildren grow up and spend time with them every day and having a visit for an hour from his bed in a skilled nursing facility or communicating with them via zoom.

3. Just this week I met with a 77 year old woman who has cerebral palsy. Despite her disability, she was able to successfully graduate from high school, attend college, have a career and even marry. In today's world, with the Americans with Disabilities Act, that doesn't seem miraculous, but to a child born with a disability in the 1940's, it was nothing short of a miracle. She and her husband were doing fine in their fully paid off, accessible condo, happily living out their retirement on their social security and his government annuity. And then her husband was diagnosed with Parkinson's and suffered some medical crises that forced him into long term care at a skilled nursing facility. My client found a roommate who would assist her with bathing and dressing each morning and then getting ready for bed each night, in return for free room and board. But her roommate isn't always available and will eventually no longer be able to provide the care that allows my client to remain at home, due to her own challenges of aging. When my client has to pay for care, it costs close to \$30/hour, and completely breaks her monthly budget. She explained that if she could just have help for 4 hours each morning and 4 hours each evening, she could continue to live in her own home for the foreseeable future. Being granted a Medicaid waiver would be the answer to her every simple prayer to be able to do so. I told her about the work I was doing with our local membership of the Aging Life Care Association together with the Maryland chapter of the National Association of Elder Law Attorneys to advocate for change. I said, if you're very lucky, 2022 will be the year that we finally more fully fund our Medicaid waiver program.

More than 20,000 Marylanders are waiting for a Medicaid waiver today. 10,000 baby boomers turn 65 every day. This is not a problem that is going to get smaller or go away. Fiscally, it makes sense to let our elderly and disabled residents remain at home with support from their families and the funds from a Medicaid waiver. And morally, it is unconscionable to keep telling more than 20,000 elderly and disabled Marylanders that they just have to keep waiting.

It's time to end the wait for the working families of Maryland, and time to pass House Bill 80.

Thank you!

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