

Testimony of the Alzheimer's Association Greater Maryland and National Capital Area Chapters
HB 80 – Home and Community Based Services Waiver – Participation and Applications
Position: Favorable

Chair Pendergrass and Vice Chair Pena-Melnyk,

My name is Eric Colchamiro, Director of Government Affairs for the Alzheimer's Association in Maryland, and here today to ask for your support of HB 80. This legislation requires the Maryland Department of Health (MDH) to increase access to its Home and Community-Based Services Waiver program.

The HCBS program concerns are not new to anyone on this Committee; yet what is new is that Maryland has a record surplus this year. This must be a priority as we consider our fiscal year 2023 policy priorities. Specifically, the Alzheimer's Association applauds the bill language to have no fewer than 7,500 people receiving services. This would be a significant improvement to Maryland's broken HCBS system, where roughly 4500 people are receiving services, and close to 24,000 are waiting.

This is fundamentally an issue of priorities. We urge the legislature to prioritize this bill, and to fix this historic injustice to Marylanders in need. I have attached the Washington Post's October 2021 article, which spoke about how most HCBS applicants go to nursing homes or die before they hear from MDH. That same article talks about how the Department is going through as many applicants "as their resource will allow..."; it is time to devote more resources to this program. Maryland spent about 18 percent of its Medicaid dollars on older adults and people with physical disabilities on home and community-based care in 2017 and 2018, ranking 33rd in the country. My goodness. We can do better.

I ask for your help today to prioritize this issue, and advance this legislation. We have a rainy-day fund for moments like this, where during a pandemic, seniors need help more than ever to stay in our communities and age in place. I am pleased that LifeSpan, representing Maryland's assisted living facility industry, is here to express provider support. I know the Maryland Association of Adult Day Services, and the Maryland Senior Citizen Advocacy Network are also in support. And the Alzheimer's Association urges a favorable report.

She's desperate to get home care for her mom. In Maryland, 21,000 are on the wait list.

By [Rebecca Tan](#)

October 9, 2021 at 6:47 p.m. EDT



Tiffanie Rivers was running out of time.

Over the past year, as the coronavirus swept through nursing homes across the country and as dementia deepened its hold on her mother, she had promised herself that she would do everything possible to keep Gayle Love, 75, at home with her in Hyattsville, Md.

She had pestered state employees about her paperwork for a Medicaid waiver, filed two years ago, that would help her afford home-based care. She had hired a consultant, who told her that the waiver that she was applying for in Maryland has a wait list of 21,000 names — one of the longest in the country — and that the vast majority of families see their loved ones check into nursing homes or die before they hear back.

In the caregiver Facebook groups that Rivers was in, people talked about a bill in Congress — recently absorbed into the \$3.5 trillion spending plan mired in debate on Capitol Hill — that would permanently bump up the federal match for home-based care and designate \$400 billion for states to expand access to such services.

In Annapolis, she heard, elder-care advocates were girding up for the 2022 General Assembly session. They had railed against the drawn-out waiver application process for years but struggled to make headway with state officials, who kept promising to address it in the next budget cycle, said Jason Frank, a retired eldercare attorney. Given the staggering coronavirus death toll in nursing homes, advocates were hopeful that legislators might finally pay attention to the wait lists.

Rivers, 46, stayed updated on these efforts. But now she couldn't afford to wait.

After toggling between working from home and caregiving for 19 months, her return to in-person work as an accountant was looming closer. She was running out of family leave, out of money and out of bandwidth. And her mother's needs were mounting. For four days last year, when Rivers was sick with a cold and bedridden, Love forgot to take her medication.

"I don't know what happens if [the waiver] doesn't kick in," Rivers said one recent afternoon, sitting outside her house. "I have to work. There's no other choice. My mom's care . . . it'll literally suffer."

Surging demand

In 2005, facing criticism that the long-term care system in the United States had an "institutional bias," the federal government made it possible — but not mandatory — for states to offer home and community-based services (HCBS) with Medicaid dollars. The goal was to let regular families access at-home help, a type of care usually reserved for the affluent. But over the past decade, experts say, these waiver programs have fallen far short of meeting demand.

Across the country, at least 820,000 people — primarily the disabled and the elderly — are on wait lists for waivers that could help them afford home care, according to the Kaiser Family Foundation. Eligibility

requirements, resources and wait times for these programs vary from state to state, but most were under-resourced even before the coronavirus pandemic, leaving applicants to wait an average of 39 months. When the coronavirus tore through skilled-nursing facilities, killing as many as one in every 10 residents, occupancy rates across the country plunged to record lows and the wait lists for home care ballooned. In Maryland, which has wait lists that rival far more populous states like Florida, elder-care attorneys and consultants say the situation has long been overwhelming.

Maryland has permission from the federal government to grant 6,348 waivers for home and community-based services, but it only enrolls 4,286 residents, according to the state's health department. More than 25,000 residents sit on wait lists to be approved.

Andy Owen, a spokesman for the department, said that the state hasn't set a cap on waivers and is going through "as many applications as our resources and those of our local partners and networks will allow." Officials need time to process applicants on the wait list and vet them based on their technical, medical and financial conditions, he said.

Owen added that there are "ongoing efforts to reduce the number of individuals on the wait list," including a new screening process that prioritizes individuals at risk of being placed in long-term care facilities. "Maryland remains committed to providing its robust system of home and community-based services," Owen said.

Elder-care advocates disagree. They say the state has not adequately invested in home-based care even though demand for these services has clearly surged.

In fiscal years 2017 and 2018, Maryland spent about 18 percent of its Medicaid dollars on older adults and people with physical disabilities on home and community-based care, ranking 33rd in the country. Most of the remaining expenditure went toward institutionalized long-term care. The District was third, and data for Virginia was not provided.

"The wait list [in Maryland] is essentially meaningless at this point," said Elena Sallitto, president of the Maryland/DC Chapter of the National Academy of Elder Law Attorneys. "People die, people move, people have dementia and don't open their mail. By the time they're at the front of the line . . . it's too late." One woman in Rockville helped her elderly mother apply for a waiver in 2014, only to receive approval five years later, at which point, both she and her mother were in nursing homes. A couple in Towson joined a waiver wait list when their disabled son was 5 and heard back when he was 14.

Most applicants in Maryland never end up accessing the benefit even when they're fully eligible, advocates say. And the situation in other parts of the country, particularly the South, is worse.

"It's heartbreaking," said Susy Murphy, an elder-care consultant based in Silver Spring. "Families come to you wanting to honor their parents' wishes. The one thing that they need, that gold ring, is just outside their grasp. And you can't — you don't know how — to say why "

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Unpaid work, ticking clocks

Part of the challenge in scaling up home care is resistance from nursing home lobbies, which worry competing models of long-term care could threaten their profits.

But the more significant issue, said Harvard University researcher David Grabowski, is that state governments

are often too financially strapped to invest in any social services that aren't mandatory, especially since states have to match federal funding with their own dollars. So even though researchers have shown for years that caring for someone in their home costs the government less in the long run than placing them in an institution, many states like Maryland have held back funding for home-based care. This still doesn't have the effect of driving people to skilled-nursing facilities.

In Maryland, the number of nursing home beds for long-term care had been declining for more than a decade before the pandemic. Rather than admit their loved ones into an institution, some families empty their savings to pay for a professional caregiver or have a relative, often a woman, cut down on work to provide care herself. "To say that, well, this care is unpaid, doesn't mean it's free," Grabowski said. "It's hugely inefficient to put this burden on families."

If and when families are able to procure the waiver, other challenges persist.

Home-care workers earn a median wage of \$12 an hour, and about a fifth of them live in poverty, according to the Economic Policy Institute. The Medicaid rate for direct-support professionals (DSPs), who make up the bulk of homecare workers, can be half or a third of what private payers offer, so many staffing agencies don't take Medicaid reimbursement.

Laura and Brian Hatcher waited nine years to get a Medicaid waiver that allows them to pay for at-home help for their son, Simon, who has cerebral palsy, autism, epilepsy and several other medical conditions. The DSP they hired in 2019 provided much-needed respite. But at the start of the pandemic, like thousands of other home-care workers, she quit. Unable to find a replacement, Brian underwent training to become a DSP so that the family could still benefit from the Medicaid reimbursement.

The family now has two ticking clocks, Laura said. One counting down to January, when the state's emergency measure allowing relatives to be reimbursed as caregivers expires. And the second counting down to 2027, when Simon turns 21 and loses eligibility for the waiver that lets him receive home-based care. He's eligible for other waivers, but they all come with wait lists.

"There simply are not enough supports to go around for everyone who needs them," Laura said at their home in Towson. "Every day, I hope against hope that before my husband and I become unsuitable to care for him, that he'll get the appropriate support."

No more time

An iPhone alarm labeled "Mom's pills" was going off for the second time.

It was midday, about the time Rivers, the accountant in Hyattsville, went from working to caregiving. She rummaged for her phone, tapping "snooze" just as an older woman walked into the living room, dressed in a coral blazer and dress pants.

"Hi, Mom," Rivers said gently. "We're not going anywhere, you know."

The woman stared at her, a small leather handbag swinging from her arm.

Love retired from a career in marketing two decades ago. But this was one of the facts of her life that dementia had made fuzzy, along with where she lived (Maryland, not Massachusetts), the name of her only child (Tiffanie) and the whereabouts of her ex-husband (alive in Nebraska, not dead).

"I am 75," she said tentatively to her daughter. "Is that right?"

"Yes. We had that big Zoom party, remember? Everyone on video?"

"Oh," Love said, nodding. "Okay then."

For Rivers, these conversations — more frequent by the day — were reminders of why she couldn't place her mother in a nursing home.

In early September, a state official told Rivers to call back about the waiver in two months, and for a while, she thought this meant her mother had a shot.

But in early October, two days after Love wandered out of the house for the first time, Rivers got another call from the Maryland health department. There'd been a mistake, the state employee told her. It would actually take much longer than two months and many more rounds of paperwork for her mother to be considered for the waiver.

Standing at her desk, Rivers felt her ears go hot and her legs throb. She had started this process two years ago and hired both a consultant and an attorney to help. She didn't know what more she could have done, or could do.

Rivers typed out an email to a state senator, ending with a plea to help in her case and change the system that had left her in this position. Then quietly, sadly, she started to research nursing homes.