



FLORIDA HEALTH
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Hundreds of organizations and individuals call on Florida's Congressional Delegation to support Medicaid Home and Community-based Care

Miami-Dade Mayor Daniella Levine Cava among the 420+ signatories

MIAMI (July 13) – More than [420 organizations and individuals](#) have signed on to a [letter](#) being delivered today that urges Florida's Congressional Delegation to support proposed major long-term funding for Medicaid Home and Community Based Services (HCBS), a critical lifeline for low-income older adults and people with disabilities who choose to live at home rather than in an institution.

Led by [Florida Health Justice Project](#) (FHJP), [Disability Rights Florida](#) (DRF) and [Florida Policy Institute](#) (FPI), the signature-gathering effort underscores the desperate need for the proposed \$400 billion in funding for programs that provide a much less expensive alternative to nursing-facility care for people who require significant assistance with the basic activities of daily living. Congress now has the opportunity to include the funding in the Better Care Better Jobs Act.

"We're sharing this letter as an effort to educate the public and elected officials about the importance of a program that is profoundly important to the families and individuals who need it, but which most people have never heard of," said FHJP director of advocacy and founder Miriam Harmatz, one of the letter's authors. "People need to know that we have this transformational chance to fix a huge problem."

Harmatz said no Medicaid programs are more critical or more seriously underfunded than those providing HCBS.

"This underfunding has left thousands of frail seniors and persons with disabilities on waitlists for HCBS," Harmatz said. "And for those who do get into an HCBS program, there is not enough funding to sustain

the workforce, including family caregivers, who provide needed home health services.”

The lack of funding has left [Alene Shaheed](#), 75, alone on many weekends, without any help to change herself or bathe, potentially exposing her to bed sores, urinary tract infections and even life-threatening conditions. The Jacksonville retiree lost the use of her legs after spinal surgery left her confined to a wheelchair, but she has lived independently in her own home with help from home health aides under Florida’s Medicaid Long-Term Care (LTC) Waiver program.

The problem is that Medicaid pays so little that many agencies won’t accept it, and those that do have trouble finding and keeping workers.

“If Medicaid paid more, they could expand the number of agencies who take Medicaid patients, and people like me would not be left alone,” Alene said. “We need funding and incentives to increase the pool of workers willing to provide care for Medicaid patients.”

While Alene would be immediately eligible for Medicaid coverage to live in a nursing home at much greater expense, she prefers to live at home with part-time aides. This saves the state money, but Alene pays the price for the underfunding of the home care program.

As dire as Alene’s situation sounds, such privation is common for those on Florida’s Medicaid waiver programs for home- and community-based care.

It can even affect relative caregivers like [Thelma Braithwaite](#), a court reporter who quit her job to take care of her mother, Hortense. With advanced Alzheimer’s, Hortense needs 24/7 care. Her managed care agency promised to pay Braithwaite \$10.76 /hour for 41 hours a week for providing this care of her mother. While it was a sacrifice, Braithwaite readily agreed because she did not want her mother to be in a nursing home. But since becoming her mother’s full-time caregiver under the Medicaid Long-Term Care (LTC) Waiver program, her hours of pay have been repeatedly cut while her mother’s condition has worsened.

She no longer earns anything close to a living wage.

“I’m so frustrated,” said Braithwaite, an Orlando resident. “Caregivers need a decent income. I feel for others who are going through the same situation.”

Meanwhile, 20,000 Floridians with developmental disabilities are on a waiting list to receive any Medicaid home- or community-based services at all, and 40% of them have already been on the list for over 10 years. And another 60,000 people are on a separate waitlist for the Long Term Care waiver program for frail seniors and adults with significant cognitive and physical disabilities.

State lawmakers have provided little in the way of funding to help remedy the issue, said Sadaf Knight, CEO of FPI.

“The COVID-19 pandemic has only exacerbated the demand for HCBS. If Congress prioritizes funding these services, the benefit will be twofold for our state: Florida’s growing senior population and people with disabilities will be able to stay in their homes, and this will reduce the demand for more costly, institutional care, therefore offsetting taxpayer costs in the long term.”

DRF Executive Director Peter Sleasman points to the need for Florida to change the way it administers the federal funding in order to reduce waiting lists and to shift the focus away from institutions toward home and community settings, which research shows are not only less costly but produce better health outcomes.

“As Florida finalizes its planning for receipt of one-time, non-recurring enhanced federal Medicaid HCBS funding, it is imperative that policymakers consider longer-term investments and other service delivery models to address Florida’s historically-underfunded waiver programs,” Sleasman said. “Comprehensive HCBS services are critical to combatting Medicaid’s long-standing ‘institutional bias,’ are less costly than institutionalization, and comply with the Supreme Court’s landmark decision in *Olmstead v. L.C.* more than two decades ago.”

Sign-on organizations to the letter urging investment in federal Medicaid HCBS funding include the office of Miami-Dade County Mayor Daniella Levine Cava, United Way of Miami-Dade, Miami-Dade’s Older Adult Advocacy Task Force, Jewish Community Services of South Florida, The ARC of South Florida, and Jacksonville Area Legal Aid.

Florida’s funding for these waiver services is among the lowest in the country, ranking 43rd in spending for HCBS programs at \$20,500/enrollee. And the situation will only get worse in Florida given that 20% of the population is 65 or over, and the growth rate for our senior population is among the highest in the country.

“That’s why we need to take advantage of this historic opportunity to fix a broken system,” Harmatz said.

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About the Florida Health Justice Project

The Florida Health Justice Project seeks to improve access to affordable health care for Floridians, with a focus on vulnerable low-income populations. FHJP expands the advocacy community’s capacity to resolve individual access issues and educate consumers; identify and address systemic barriers to healthcare; and protect Medicaid and other safety-net programs.

About Disability Rights Florida

Disability Rights Florida was founded in 1977 as the designated protection and advocacy system for individuals with disabilities in the State of Florida. The nonprofit organization provides legal and advocacy services to people with disabilities at no cost through the authority and responsibility of nine federal grants. DRF's mission: Disability Rights Florida advocates, educates, investigates and litigates to protect and advance the rights, dignity, equal opportunities, self-determination and choices for all people with disabilities.

About Florida Policy Institute

Florida Policy Institute is an independent, nonpartisan and nonprofit organization dedicated to advancing state policies and budgets that improve the economic mobility and quality of life for all Floridians.