



FLORIDA HEALTH  
JUSTICE PROJECT



Dear Members of Florida's Congressional Delegation:

As Florida and the country heal from the pandemic, the American Jobs Plan's proposal for supporting and expanding Medicaid Home and Community-Based Services (HCBS) is absolutely critical. The undersigned Florida organizations and individuals urge our members of Congress to understand the importance of approving the proposed \$400 billion in HCBS funding.

Medicaid HCBS programs provide a much less expensive alternative to nursing facility care for low-income individuals who require significant assistance with the basic activities of daily living. For eligible individuals, the cost of nursing home care is several times the cost of the alternative HCBS program.[\[1\]](#) In Florida, the two major HCBS programs that serve as the only alternatives to institutional care are the iBudget waiver and the Long-Term Care (LTC) waiver.

The iBudget waiver provides medically necessary supports and services to people with developmental disabilities to prevent institutionalization and to promote their health in a home-based setting. [\[2\]](#) The LTC waiver provides such services and supports to seniors and other eligible individuals.[\[3\]](#) These programs, which include services that are not typically available through Medicare or standard medical insurance, such as personal care aides, home-delivered meals, and private duty nursing, are absolutely essential for the state's most vulnerable populations. Tragically, for thousands of Floridians and their families, the two programs are also terribly underfunded.

While eligible individuals can enroll immediately in the state's institutional care program and receive placement in a nursing home, most people far prefer to remain in their homes. The option of receiving services at home is not simply a matter of personal preference, research has shown that quality of life is significantly impacted. [\[4\]](#) And the pandemic provides a stark example of how health outcomes are also adversely impacted by institutionalization. Almost 11,000 Florida nursing home residents died due to COVID. [\[5\]](#)

Unfortunately, most people applying for HCBS are on long waitlists. Currently in Florida, over 20,000 individuals with developmental disabilities are on the waitlist for the iBudget waiver, an increase of 1,200 individuals between July 2019 to July 2020. Forty percent of these individuals have already been on the list for over 10 years. [\[6\]](#) [\[7\]](#) Approximately, 60,000 individuals are on the waitlist for the LTC waiver program. [\[8\]](#)

In addition to long waitlists due to Florida's lack of adequate funding, and despite having one of the country's largest qualifying populations, 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.[9]

The underfunding of the programs has also created serious problems in Florida's HCBS workforce. When services are not adequately funded, it can be difficult to find workers to provide services, especially during certain times, or for particularly intensive needs, or in certain geographical locations. This results in dire situations as profoundly vulnerable program enrollees, who rely on HCBS services, are left alone for days. This includes those who are incontinent and need assistance to change and bathe. For example, [Shirley](#), a woman who is bed-bound following a stroke, relies entirely on home-health aides to operate the special lift to get her out of bed. Her Medicaid managed care plan is unable to find aides to take care of her on the weekends, forcing her to stay in bed for the entire weekend and increasing her risks for bed sores and skin infections. [10]. Similarly, [Alene](#), who lost the use of her legs and uses a wheelchair has been stranded without assistance for days at a time, including virtually every weekend for the past several months.[11].

[“We need funding and incentives to increase the pool of workers willing to provide care for Medicaid patients.”](#) Alene explained. Medicaid just does not pay enough to sustain a workforce, and things are far worse since COVID. Workers are terribly underpaid, making an average of only \$12 an hour. Most do not have benefits. An increase in funding to HCBS services is essential to build the robust workforce of home health aides needed for current HCBS enrollees who desperately rely on their services.

The situation will only get worse in Florida. Approximately 20% of the population is 65 or over, and the growth rate for our senior population is among the highest in the country. [12] Statistically, over half of people turning 65 will at some point develop a severe disability or medical condition that will require HCBS.[13] Despite Florida's growing senior population, the state is currently ranked last in long-term services and supports (LTSS) for older adults, people with physical disabilities, and family caregivers. According to [AARP's 2020 scorecard](#), Florida is 51st in LTSS and has consistently ranked in the bottom for the past decade. [14].

For those older adults and people with disabilities who live at home, the responsibility of care and support falls on family caregivers and the inadequacy of our system falls disproportionately on people of color with limited income and wealth. For example, [Thelma](#) quit her job to care for her elderly mother who requires 24/7 care. Although she was promised 41 hours of pay, the managed care plan continued to cut her hours as her mother's Alzheimer's progressed and her health worsened. [15]

In sum, while a major increase in HCBS funding is needed throughout the country, the predicament in Florida is particularly dire. The state is ranked 43rd in spending, last in long-term

services and supports, and currently has tens of thousands of eligible individuals on the waitlist for HCBS waivers.

We urge Florida's lawmakers and leadership to support the proposed \$400 billion investment in the infrastructure of Medicaid HCBS and the workforce that provides these essential services.

Respectfully,

Florida Health Justice Project  
Disability Rights Florida  
Florida Policy Institute

*And:*

1199SEIU United Healthcare Workers East  
A Guardian's Hope, Inc.  
A.F.I.R.E. Of Pasco County, Inc.  
Adult Care Housing, Inc.  
Advocare Trust, Inc.  
Allegany Franciscan Ministries  
Anitya Doula Services  
AnnMary, Inc.  
Blessing Hands Solutions  
Careride  
Catalyst Miami  
Champion Care, LLC  
Clay County Change Makers Self Advocacy Group~United by Different ABilities  
Columbus Organization  
Coworkers, Inc.  
Democratic Disability Caucus of Florida  
Democratic Progressive Caucus of Tampa Bay  
Destined for Change, LLC  
Elder Law Associates, PA  
Family Care Council Area 1  
Family Care Council Area 14  
Family Care Council Area 15  
Family Care Council Suncoast West  
Family Care Council, Area 9 (Palm Beach County)  
First Coast Angels, LLC  
Florida Alliance for Assistive Services and Technology, Inc.  
Florida Center for Fiscal & Economic Policy  
Florida Center for Inclusive Communities

Florida People's Advocacy Center  
Florida Physical Therapy Association  
Florida Self-Advocates Network'D (FL SAND)  
Gold Coast Down Syndrome Organization  
Gray Panthers of South Dade  
Gulfcoast Legal Services, Inc.  
Harris Support Services  
Heart N Home Supported Living Services, Inc.  
Helen Norris World Of Care Agency, LLC  
Home Care Association of Florida  
Honest Touch, LLC  
Hope 4 Life, Inc.  
J & M Support Coordination Services  
Jacksonville Area Legal Aid, Inc.  
Jewish Community Services of South Florida  
Kaelin Support Services  
Law Office of Kimberley Spire-Oh, PA  
Living Dignified at Home, Inc.  
Lupus and Allied Diseases Association, Inc.  
MCS Music Therapy, LLC  
Miami Dade County  
Miracles In Motion  
Monroe Association for ReMARCable Citizens  
Morgan Law Center for Estate, Elder & Legacy Planning, PLLC  
Neurologic Music Therapy, LLC  
Older Adult Advocacy Taskforce  
Open Arms Care, LLC  
PARC  
Peace of Heart Community  
Prospering At Life, Inc.  
Relatable Communications Group  
Ridgeland Group Home, Inc.  
RISE Center IRC  
Rockwell Health Solutions  
Sanzell Group Home Services, Inc.  
Shalimare, Inc.  
Sheryl J. Manning, P.L.  
Solkoff Legal  
Specially Fit  
Stand Up For Independence, Inc.

Struggle for Miami's Affordable and Sustainable Housing, Inc.  
Sunset Support Services  
Teresa K Bowman, PA  
The Advocacy Network on Disabilities  
The Arc of South Florida  
The House of Music Therapy, LLC  
Tri County Senior Resource Referral Network, LLC  
United Way of Miami-Dade  
Wesley Chapel Support Services, LLC  
Yasmina, Inc.  
Your Life's Choices, Inc.

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## Endnotes

[1] *See* Statewide Medicaid Managed Care (SMMC) Long-Term Care (LTC) Program Monthly Base Rates, (Oct. 2020 - Sept. 2021)(finding that The cost of a Nursing Facility in Florida is approximately three (3) times the cost of long-term care services under the waiver)  
[https://ahca.myflorida.com/medicaid/Finance/data\\_analytics/actuarial/docs/LTC\\_Final\\_Base\\_Rates\\_RY20-21.pdf](https://ahca.myflorida.com/medicaid/Finance/data_analytics/actuarial/docs/LTC_Final_Base_Rates_RY20-21.pdf). *See also* *LTC Capitation Rates and Related Services - Budget Estimate Detail, obtained from AHCA by Justice in Aging in 2019* (finding that as of June 2019, the Nursing Facility rate was \$6,119 and the HCBS rate was \$1,650. The Statewide Medicaid Managed Care LTC rate paid managed care entities 44.6% of the Nursing Facility rate (\$3,599.81)).

[2] Developmental Disabilities Individual Budgeting (iBudget) Waiver,  
[https://ahca.myflorida.com/Medicaid/hcbs\\_waivers/ibudget.shtml](https://ahca.myflorida.com/Medicaid/hcbs_waivers/ibudget.shtml).

[3] Florida Health Justice Project, *Advocate's Guide: Florida Long-Term Care Medicaid Waiver (4th Edition Jan. 2021)*  
[https://www.floridahealthjustice.org/uploads/1/1/5/5/115598329/4th\\_edition\\_ltc\\_guide\\_2.16.21\\_1.pdf](https://www.floridahealthjustice.org/uploads/1/1/5/5/115598329/4th_edition_ltc_guide_2.16.21_1.pdf) at 5-6.

[4] *See e.g.* Research and Evaluation of the Money Follows the Person (MFP) Demonstration Grants,  
<https://mathematica.org/projects/research-and-evaluation-of-the-money-follows-the-person-mfp-demonstration-grants>

[5] The COVID Tracking Project, The Atlantic (Mar. 7, 2021),  
<https://covidtracking.com/data/state/florida/long-term-care#-82.4497.28.6305.5>

[6] *About the iBudget DD Waiver and Waitlist*, Florida's DD Waitlist Campaign (Jan. 2021)  
[http://ddwaitlist.cbcs.usf.edu/about.html#:~:text=22%2C718%20people%20\(as%20of%20January,60%25%20are%20receiving%20services\).](http://ddwaitlist.cbcs.usf.edu/about.html#:~:text=22%2C718%20people%20(as%20of%20January,60%25%20are%20receiving%20services).)

[7] House of Representatives Staff Analysis (Mar. 2021)  
<https://www.flsenate.gov/Session/Bill/2021/117/Analyses/h0117c.HHS.PDF> at 2.



[8] *Department of Elder Affairs Statewide Analysis Assessed Prioritized Consumer List Totals by Assessed Rank Level and Program* (Apr. 23, 2020) [https://fcoa.starchapter.com/images/other/waitlistreport\\_042020.pdf](https://fcoa.starchapter.com/images/other/waitlistreport_042020.pdf) at 1.

[9] Molly O'Malley Watts, et al., *Medicaid Home and Community-Based Services Enrollment and Spending* <https://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending> at 16.

[10] <https://archive.floridahealthstories.org/shirley>

[11] <https://archive.floridahealthstories.org/alene-ltc-2>

[12] Christine L. Himes & Lilian Kilduff, *Which U.S. States Have the Oldest Populations?*, Population Reference Bureau (Mar. 16, 2019) <https://www.prb.org/resources/which-us-states-are-the-oldest/>

[13] Long-Term Services and Supports State Scorecard 2020 Edition [http://www.longtermscorecard.org/~/\\_media/Microsite/Files/2020/LTSS%202020%20Short%20Report%20PDF%20923.pdf](http://www.longtermscorecard.org/~/_media/Microsite/Files/2020/LTSS%202020%20Short%20Report%20PDF%20923.pdf) at 20. The LTSS scorecard is a complete and comprehensive assessment of LTSS system performance across five key characteristics: (1) Affordability and Access, (2) Choice of Setting and Provider, (3) Quality of life and Quality of Care, (4) Support for Family Caregivers, and (5) Effective Transitions.

[14] *Id.* at 12-13.

[15] <https://archive.floridahealthstories.org/thelma>