Project Independence
Florida Health Justice Project

Improving the Future of the Florida Medicaid Home & Community-Based Services Long-Term Care Waiver Program

July 1, 2019 - June 30, 2023

ROCKWELL HEALTH SOLUTIONS

FLORIDA HEALTH JUSTICE PROJECT

RRF Foundation for Aging

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INTRODUCTION

Project Independence is a four-year advocacy project developed in 2019 by the Florida Health Justice Project (FHJP) to identify and address systemic barriers to Medicaid home and community-based services (HCBS) for low-income Florida seniors who need assistance with the basic activities of daily living and who want to receive that assistance at home rather than in an institution. Funded annually by the RRF Foundation for Aging[1], FHJP, an advocacy organization for expanding healthcare access and promoting health equity for vulnerable Floridians, identified and implemented a set of advocacy priorities to help improve access to HCBS.

As part of the final year of Project Independence, FHJP contracted with Rockwell Health Solutions, LLC to both assess the Project and develop a Road Map that can be used to build upon the extensive institutional knowledge and experience gained by FHJP through Project Independence. The methodology used to develop the Road Map included a review of all related comment letters, bulletins, and tools on the FHJP website in addition to a review of pertinent stakeholder presentations. Lastly, a variety of stakeholders were interviewed to help evaluate the efficacy and value of FHJP's advocacy efforts on behalf of the LTC Waiver.

Background

The Florida Medicaid Long-Term Care (LTC) Waiver Program provides HCBS that are not typically available through Medicaid, Medicare or standard medical insurance, such as personal care aides, home-delivered meals, and private duty nursing to low income/low wealth individuals who require significant assistance with basic activities of daily living. The demand for services is far greater than the current budget in the state of Florida, and unlike other Medicaid services, including institutional nursing home care, the state is allowed to create a waitlist for HCBS. In addition to the lack of funding to enroll the tens of thousands of Floridians currently seeking HCBS who are waitlisted for the LTC Waiver Program, the application process creates barriers to obtain services for an individual or their caretaker, and barriers are also faced by those who are successfully enrolled in the Program.

[1] RRF Foundation for Aging is a national organization focused on improving the quality of life for older people. Additional grant support was leveraged, including funding from the United Way Miami-Dade County to provide technical assistance and create the content for an Older Adult Task Force, and from the Miami Alliance for Aging to create the consumer facing video on how to apply for HCBS.

Action Agenda

- Create tools for advocates, providers, and consumers to explain the mechanics of the Medicaid LTC Waiver and consumer rights for applicants and enrollees;
- Identify barriers to obtaining medically necessary services under the LTC Waiver;
- Pursue administrative advocacy with the Medicaid agency to address barriers; and
- Increase public awareness for the need for greater HCBS resources through educational events, such as roundtables, meetings with elected officials/staff, and story sharing.

Tsunami of Need

According to FHJP's Florida Seniors Tsunami of Need: Statistics & Transparency, approximately 20% of Florida's population is age 65 or over and is expected to increase to 30% by 2030, one of the highest growth rates for seniors in the country. Statistically, over half of people turning 65 will at some point develop a severe disability or medical condition that will require HCBS, and Florida ranks 51st in the country for long term services and supports. In addition, 12.7% of Florida seniors live in poverty, including 18.6% of Black seniors and 21.6% of Hispanic seniors. While Medicaid covers institutional nursing home care for those that meet the requirements as an "entitlement" (i.e. no wait list), most eligible individuals much prefer to receive HCBS. However, those who elect HCBS over institutionalization, struggle to stay at home while they linger on a lengthy and cumbersome wait list. Notably, HCBS is approximately one-third of the cost of nursing facility care in Florida. Until the state stopped tracking COVID-19 data in nursing homes, Florida led the nation in nursing home resident and staff COVID-19 deaths, accounting for 21% of total deaths.

External Impacts on LTC Waiver Program

During the four-year project period, the COVID-19 pandemic started and ended. This unprecedented health crises impacted the LTC Waiver Program and the healthcare

barriers faced by the LTC population. The federal policies that were enacted to assist this population during the pandemic also ended during the project period. The COVID-19 pandemic created a new window to address opportunities and challenges that arise when an international public health pandemic occurs in a Nation without universal access to healthcare and in a State with limited resources for those in need. Although the Federal Better Care Better Jobs Act, which would have provided significant increased funds for state Medicaid programs to improve HCBS, failed to pass in late 2022, it provided an excellent opportunity for education on the impact of HCBS and Florida's profound need for more funding. In addition, over the course of the project, the State also made policy changes which have/will impact the target population, including a significant increase in wages for Medicaid home health workers. Fortunately, FHJP has been able to continue advocating for the LTC population during these changes, thanks to the support from RRF for Project Independence.

COVID-19 Medicaid Continuous Coverage Winddown

During Year Two of Project Independence, in March 2020, a Public Health Emergency (PHE) was declared for COVID-19. Pursuant to early pandemic related legislation, states were required to ensure continuous coverage of all Medicaid enrollees during the PHE, regardless of eligibility or failure to timely complete the annual redetermination process. The PHE was extended multiple times until December 2022 when Congress "de-linked" the continuous Medicaid coverage requirement from the PHE and set an end date of March 31, 2023.

As of that date, the Florida Department of Child and Family Services (DCF), which oversees Medicaid eligibility for the state, began reviewing the current eligibility of all recipients, a 12-month process referred to as "Medicaid Unwind". On April 30, 2023, the first Medicaid terminations began. While most advocacy groups and community navigators have been exclusively focused on the large number of Florida parents and caregivers who have lost or will lose family related Medicaid, FHJP has also focused on issues impacting those who receive Medicaid based on age and disability. FHJP has been the state leader in providing tools and trainings for advocates and navigators assisting all Medicaid recipients during the unwind.

ACTION AGENDA

Tools, Training, and Technical Assistance

FHJP has expanded the capacity of the advocacy community to represent clients needing Medicaid HCBS. FHJP develops materials and provides trainings and technical assistance to legal services and elder law attorneys throughout the state of Florida who represent HCBS clients and may be unfamiliar with the complexities of the law.

"The strength of FHJP is to be in the position to help and support the legal aid delivery system. The materials are good for individuals and families, but best to support local legal aid attorneys to train, educate, and assist in cases in the complicated law that they know so well. FHJP has the strength and expertise to do the trainings and issue briefs."
- Former State Legal Services Developer at the Florida Department of Elder Affairs

Advocate's Guide to the Florida Long-Term Care Medicaid Waiver

FHJP has created and updated tools for advocates, providers, and consumers to help them understand the mechanics of the LTC Waiver and consumer rights under the Waiver, both for applicants and enrollees. Most notably, FHJP created the Advocate's Guide to the Florida Long-Term Care Medicaid Waiver with funding from the Florida Department of Elder Affairs, and the RRF Foundation for Aging has supported five major updates to the Guide.

"The writing was extremely clear and concepts that are obscure are presented with clarity and practical solutions that allow a non-lawyer to do what they need to do and a lawyer to give pragmatic advice that can be helpful."
– Elder Law Attorney based in Tampa, FL

Now in its fifth edition, the Guide and its accompanying consumer-focused explainer video, created with support from RRF and the Alliance for Aging, provides clients, caregivers, frontline workers, and providers with resources for navigating the *extremely* complex application, approval, and appeals processes related to obtaining HCBS through the Medicaid LTC Waiver. To date, there have been 2,133 unique page views to the landing page of the Guide and 5,330 unique page views to the consumer video.

Addressing Systemic Barriers

Project Independence identified barriers for LTC Waiver applicants and enrollees and used a variety of strategies to address systemic barriers.

Advocating with the Florida Medicaid Agency and Educating Florida's Elected Officials: Sign-on and Comment Letters

FHJP worked directly with the Florida Medicaid Agency to educate agency staff and other advocacy partners regarding barriers to care for Florida seniors and persons with disabilities needing HCBS.

During the project period, FHJP released six comment letters addressing the need for increased HCBS resources and identifying barriers to care in Florida's Medicaid LTC Waiver Program.

> *"Comment letters are a huge value add for other advocacy organizations. A lot of states don't have a partner that has the capacity to engage on developing comment letters or the detailed understanding of the law behind the legislation. FHJP provides Justice in Aging with the ability to create templates to share with partners to further national advocacy efforts."*
> *-Director Federal Health Advocacy, Justice in Aging*

- American Rescue Plan Act (ARPA) Funding
  On April 1, 2021, ARPA funding went into effect in Florida, which authorized a ten-percentage point enhancement to the Federal Medical Assistance Percentage (FMAP) for HCBS between April 1, 2021 and March 31, 2022. In May 2021, FHJP submitted the first of two comment letters to Florida's Agency for Healthcare Administration (AHCA) to encourage consumer input; advocate for using the funds to increase wages and benefits; require plans to provide the live-in caregiver service; create outreach and educational materials; and address social determinants of health (SDOH). A follow up comment letter was submitted in June 2021 to stress the importance of the specific priorities areas raised and working together towards shared public policy goals.

- Florida's 1915 (b)(c) Long-Term Care (LTC) Waiver Renewal
  FHJP played a lead role in responding to proposed rule changes to the LTC Waiver. In September 2021, FHJP filed an extensive comment letter on the State's request to renew the waiver for an additional five years. FHJP identified problematic issues in the renewal request, including funding that favored managed care plans to institutionalize patients over home care; a lack of an ombudsman program; termination of external review protections for denials; and denial of network adequacy problems.

- Support for the American Jobs Plan's Proposal to Support and Expand Medicaid HCBS

  In July 2021, FHJP wrote a comment letter to Florida's Congressional delegation describing the need for increased funding for Medicaid HCBS and identifying key state partners to assist with dissemination, which garnered over 400 sign-ons from Florida organizations and individuals. The letter explained the increased need to provide HCBS to qualified individuals, as there are currently over 60,000 individuals on the waitlist who need to be processed through the system and provided HCBS if applicable. However, without increased workforce funding for home care workers and incentives for agencies to accept Medicaid patients, there will not be enough qualified caregivers to serve the population, furthering the reliance on family caregivers, which disproportionately impacts the poor community and creates an incentive for the managed care plans to assign a lower assessment score.

- Hearing on "An Economy that Cares: The Importance of Home-Based Services"

  In March 2022, FHJP submitted public comments to United State Senators Bob Casey and Tim Scott of the U.S. Senate Special Committee on Aging which praised the Senators' comments during the March 23rd hearing and urged the Committee to keep educating other members of the Senate on the need to pass increased Medicaid HCBS resources through the Better Care Better Jobs Act.

- Florida's Transition Plan for Home and Community Based Settings

  In April 2022, FHJP, along with Disability Rights Florida, Florida Policy Institute, Jacksonville Area Legal Aid, and Legal Services of Greater Miami, Inc., issued a joint comment letter to the AHCA addressing Florida's noncompliance in the statewide transition plan for HCBS. The comment letter specifically addresses how Florida's Transition Plan erroneously states that Florida faces no "significant impediments" to compliance with the HCBS Eviction Rule and offers recommendations to gain compliance.

Older Adults Advocacy Taskforce

FHJP leveraged federal efforts to increase HCBS resources in partnership with the United Way Miami Dade County (MDC) Older Adult Advocacy Task Force, a collaboration of more than 20 experts to explore policy solutions for older adult issues in MDC. Notably, the need for increased resources is the greatest in MDC in terms of the number of low-income vulnerable seniors at risk of institutionalization and homelessness. For the first time in history, Miami-Dade Older Adults (age 60+) outnumber all children (ages 0-17). FHJP provides legal advice to the taskforce when applicable.

"The Roundtable showcased something that was so unique about FHJP - they understand the federal, state, and local advocacy and that it all intertwines and matters. No other organization can demonstrate that to this level in other states"
- Director of Federal Health Advocacy, Justice in Aging

In June 2022, FHJP, with support from the United Way Miami, provided the technical expertise, planned the content, and secured speakers for the Older Adults Advocacy Taskforce forum hosted by United Way and Miami-Dade

County Mayor Daniella Levine Cava, with panels focused on the tremendous need for increase HCBS resources in MDC. FHJP was highlighted as the technical expert on the Medicaid LTC Waiver and their work in shaping the forum.

Promoting Legal Rights in the Enrollment Process

Ensuring the Right to Post Screening Notices

Prior to this project, few people who applied for HCBS through the Medicaid LTC Waiver Program were sent a written notice explaining the outcome of the assessment screening; their priority "score"; their status on the waitlist; and the right to appeal. In addition, during the first year of the project, the Florida legislature passed an amendment stating that applicants with low priority scores would no longer be placed on the wait list. FHJP took a leadership role in the rule making process to ensure basic due process was provided for all applicants, i.e. requiring that everyone who applied would be provided with a written notice, including the right to appeal their score. They drafted comment templates addressing this issue in the proposed rule and shared the templates with partners (elder law attorneys, legal services health and elder attorneys, and elder advocates); testified at rule workshops; filed written comments; and worked with the media to explain due process issues and the importance of proper notification of status and right to appeal.

Now, under Florida's final LTC Waiver application rule, anyone who applies for Medicaid HCBS is sent a written notice containing the same information, including whether or not the individual's score results in placement on the waitlist. FHJP completed a public records request review of over filed appeals and were able to confirm that notices are sent and appeals are resulting in positive outcomes.

Increase Access and Transparency for Fair Hearing Decisions

Filed Suit Against Florida's Agency for Health Care Administration (AHCA) for Lack of Access to Public Records

In December 2020, FHJP filed suit on behalf of Nancy Wright, an elder law attorney who represents Medicaid LTC Waiver Program recipients at fair hearings before AHCA. The complaint was in regard to the lack of access to final decisions from fair hearings that are appealed when recipients' Medicaid benefits are denied, terminated, or reduced by their managed care plan. Currently, hearing decisions must be requested and individuals must pay redaction fees. This process creates a barrier in obtaining the records of prior hearings, records which are critical in better understanding the standards and reasoning employed by individual AHCA hearing officers. FHJP argues that publishing the decisions online for free, which is a similar practice for other state agency hearing records, would also hold the AHCA accountable for applying the rules fairly. WUSF Public Media covered the lawsuit on January 5, 2021 on air and online, which demonstrates public interest in accessibility and transparency of Medicaid fair hearing records. FHJP recruited pro bono attorney, Bryan Gowdy, a board certified appellate law attorney who has twice argued in front of the U.S. Supreme Court, to handle the matter in the First District Court of Appeal.

In June 2023, Florida's First District Court of Appeals ruled against requiring the publication of hearing decisions. This unfortunate decision reflects the barriers to implementing systemic change within Florida to better serve the individuals most in need. FHJP's advocacy work in this area will continue, as public access to Fair Hearing Decisions should be made available free of charge and in line with other state agency hearing records.

Represent Individual Cases that Demonstrate Systemic Barriers

Improper Reliance on Family Caregivers

FHJP successfully represented a small number of LTC Waiver enrollees whose needed services had been denied, terminated, or reduced. Through the course of litigation, each of these cases illustrated what appear to be systemic issues in the managed care plan's improper reliance on "natural support" systems, typically family caregivers who are women of color, as well as the plan's impermissibly narrow coverage standards for services such as home delivered meals.

In January 2023, FHJP, Jodi Siegel from Southern Legal Counsel, Inc., and Nancy Wright from the Law Office of Nancy E. Wright, collaborated on a demand letter to the AHCA Acting General Counsel on behalf of Alfonso Hernandez v. Humana (Appendix 3). Mr. Hernandez is enrolled in the Medicaid LTC Waiver Program and Humana has been managing his care plan. His approved personal care hours were insufficient given his diagnoses and Humana improperly used the fact that Mr. Hernandez's son was providing some in-home support to reduce home health services. This case represents an overarching concern of FHJP that MCOs improperly use the presence of others (typically family members) in the LTC Waiver recipient's household to reduce home health services based on a legally erroneous definition of "natural supports." After repeated requests to Humana went unanswered, followed by a formal AHCA complaint against Humana, a Fair Hearing revealed systemic failures in Humana's decision making process and AHCA's understanding of the Long-Term Care Program Coverage Policy. The demand letter served to request immediate action by the AHCA Acting General Counsel to authorize 24/7 personal care for Mr. Hernandez in addition to developing written protocols pertaining to the issues that arose during the Fair Hearing, in addition to training AHCA staff on the LTC Coverage Policy. AHCA Acting General Counsel quickly responded and provided all of the hours requested in the letter in order to moot out the systemic demands. FHJP continues to work on the systemic issues identified in the letter, including the state's erroneous use of "natural supports" to reduce home health hours of LTC Waiver recipients.

Lack of Legal Representatives at Hearings

FHJP reviewed 163 Medicaid Fair Hearing decisions provided pursuant to a public records request asking for all decisions related to Medicaid managed care LTC hearings between June 2020 and June 2021 and provided a short brief summarizing the review. These hearings involved beneficiary appeals of adverse benefit determinations by Medicaid managed care plans. The key findings were that an extremely small number of beneficiaries had legal counsel (only four out of 163, (2.5%)) and the very few who did have legal counsel had a much higher success rate than those who were unrepresented

(50% vs. 25%). The review identified those factors common to the prevailing party in Medicaid Fair Hearings, i.e. presenting witnesses and documentary evidence. The vast majority of beneficiaries who lacked legal counsel presented no evidence and had no witnesses. By contrast, enrollees who are represented by an attorney (as well as the plans) presented witnesses and submitted documentary evidence. FHJP's review found that beneficiaries who lack legal counsel are generally not able to present the facts of their case, and/or make arguments supporting their entitlement to services based on the governing law and contracts. Pro se beneficiaries are severely handicapped in being able to secure the care that they need through the Fair Hearing process.

Notice of Adverse Benefit Determination Must be Updated to Include Legal Aid Information

The Notice of Adverse Benefit Determination does not provide a link to legal services, and LTC plan enrollees or their families are entitled to legal counsel in their appeals. FHJP has filed a Request for Correction Action on the template Notice of Adverse Benefit Determinations articulating the benefits—both for enrollees, plans, and the state, if the notice were amended and enrollees understood that they could request free legal assistance (Appendix 2).

Workforce Support

Increase Wages and Hours

Frontline home healthcare workers are terribly underpaid, resulting in a severe shortage of workers available to serve patients that get off the waitlist and enroll in a Medicaid LTC Managed Care Plan. As a result, many Floridians who require daily home health services rely on unpaid or underpaid family members, or go days at a time without aides.

Numerous stakeholders, including FHJP, successfully advocated for increased frontline worker pay, including for family members. The 2022 Florida Legislature approved the increase and in late 2022, the Florida Medicaid Program approved a minimum wage of $15 per hour for direct care employees of Medicaid providers. This included family members and others providing care through the managed care plans' Participant Directed Option (PDO) program such as Thelma.

Public and Media Outreach and Education

In addition to advocating directly to the Florida Medicaid Agency and statewide legislators, FHJP has developed a series of outreach and educational materials geared toward helping the public, media, and HBCS applicants and enrollees better understand the need for increased HCBS resources.

Public Resources

Flyers

- Medicaid Home & Community Services (HCBS): Know Your Rights! 4/14/20
- Have You Applied for Home & Community-Based Services (HCBS)? Information that You Need to Know 11/8/21 (English and Spanish)
- Florida Seniors - Tsunami of Need: Statistics & Transparency 2/1/22
- Right to Home/Community Placement for Nursing Home Residents 9/7/22

Guides

- The Advocate's Guide to the Florida Long-Term Care Medicaid Waiver – Fifth Edition July 22

Issue Briefs and Fact Sheets[2]

- Expanding Medicaid: More Critical Than Ever for Older Floridians in the Time of Coronavirus 5/26/20
- Summary of 2020 Change to Prioritization and Notice of Wait List for Individuals Applying for Florida's Long-Term Care Waiver 7/13/20
- Why Medicaid Expansion Matters to Older Floridians 10/1/20
- Why Medicaid Expansion Matters to Floridians Already on Medicare 10/6/20
- Importance of Increased Funding for Florida's Medicaid Home and Community Based Services (HCBS): Florida Needs the Better Care Better Jobs Act 8/1/21
- Medicaid Home and Community Based Services: Issue Background; Need for Increased HCBS in Miami-Dade County; Better Care Better Jobs Act Opportunity 6/23/22
- Right to Home/Community Placement for Nursing Home Residents 9/7/22

Videos

- Florida's Medicaid Long-Term Care Home and Community Based Services (HCBS) Navigating the Program 1/1/21
    - Consumer-focused explainer video for patients and caregivers to help understand the HCBS Medicaid LTC Waiver assessment and

[2] While Medicaid Expansion is not directly related to the project, Florida's failure to enact Medicaid expansion has led to an increased need to advocate on behalf of aged (60-65) and disabled Floridians and their families. Florida's Medicaid eligibility for aged and disabled only goes to 88% of the federal poverty level. Medicaid expansion, which covers individuals 19-65, would allow for far more individuals to access to some home health services under the regular Medicaid program.

enrollment process, including their rights under the law. The video complements the more complex Advocate's Guide to the Florida Long-Term Care Medicaid Waiver.

- Home & Community Based Services (HCBS) in Miami-Dade County 6/22/22
    - Brief video explaining the importance of Medicaid HCBS, the need in Miami-Dade County for increased HCBS; and how the lack of resources is hurting Miami families.

Legislative Advocacy[3]

- Take Action for Home and Community-Based Services! 3/23/22
    - Sample letters to send to Florida Senators Marco Rubio and Rick Scott regarding the need to support HCBS in the Better Care Better Jobs Act. Both Senators are members of the US Senate Special Committee on Aging.
- Florida Health Justice Project's Comment regarding March 23, 2022 Hearing on "An Economy that Cares the Importance of Home-Based Services" 3/30/22
    - Public comments directed to the US Senate Special Committee on Aging regarding increased need for HCBS funding and increased frontline worker and family caregiver wages.

Press Release and Media Coverage

- Florida Health Justice Project Urges Floridians Take Action to Increase Funding and Support for Home and Community-Based Health Care Services 3/28/22 (English and Spanish)
- Florida Group Works to Keep Eligible People on Medicaid 3/16/23
    - Public News Service article highlighting the increased risk of delayed renewals or terminations for aged and disabled Medicaid recipients during the Medicaid "Unwind".

[3] In accordance to the RRF grant funding guidelines, FHJP did not use any of the funding associated with Project Independence to perform any lobbying activities. Any political advocacy was conducted under other funding sources during the project period. For example, FHJP received funding from the Miami United Way OATF to provide technical expertise in a series of meeting with South Florida's members of Congress (primarily their staff) regarding the import of HCBS, the need for increased resources, and the potential impact of the Better Care Better Jobs Act on increasing wages for frontline homecare workers.

STORIES PROJECT

Story sharing is an essential strategy in FHJP's advocacy. Sharing the real-life experience of those who need Medicaid HCBS is critical; it sheds light on the importance of the benefits and helps identify and address systemic barriers. As part of the Project, fourteen stories have been documented and shared regarding challenges in navigating and accessing HCBS under the LTC Waiver in Florida. The stories of clients are woven into each of the different advocacy efforts, such as comment letters on the Waiver renewal request and urging the state to draw down additional federal HCBS funding; and a sign on letter to Florida's Congressional delegation urging support for additional HCBS funding.

As discussed, FHJP has represented individuals in appeals when clear systemic issues are present, such as the LTC managed care organizations (MCO) overreliance on family caregivers or overly restrictive standards for providing home delivered meals. The three cases highlighted below demonstrate how FHJP combines story sharing with litigation to both advance the project's advocacy priorities and help individuals obtain needed services. The client's story is published on the FHJP stories website, then shared with the attorney representing the MCO and the AHCA. Each of these cases were settled by the MCO prior to the hearing

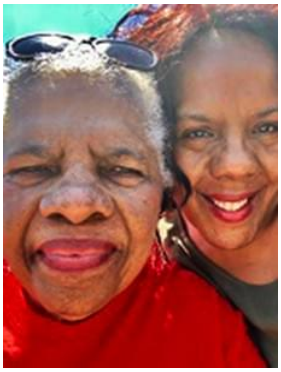
Unwarranted Loss of Services

Haydee and Barbara, Miami, FL

Haydee, 89, suffers from advanced Alzheimer's and other age-related conditions. After a yearlong wait to be approved for HCBS, she receives services including home delivered meals, incontinence supplies, and homemaking hours. While Haydee was approved for HCBS, this doesn't mean that she has consistent or quality homecare services. Her daughter Barbara, who provides care assistance, found that the MCO denies "almost everything." Services that were routinely provided are suddenly canceled. The number of hours for home health aides are also cut, leaving Barbara to pick up the pieces.

Barbara fought the loss of services by appealing the denial. FHJP represented Haydee in her Medicaid Fair Hearing Appeal. During the course of discovery, the managed care plan decided to reinstate her home delivered meals for a year. As a result, Haydee is able to receive the nutrition she needs without the need for a hearing.

Service Hour Reduction



Thelma and Hortense, Orlando, FL

Thelma became her mother, Hortense's, full-time caregiver when Hortense's advanced Alzheimer's progressed to the point where she could not be left alone. Hortense, who is enrolled in the LTC Waiver Program requires full-time caregiving in order to remain safely at home. A representative from the MCO assured Thelma that if she left her job as a court reporter to care for her mother, she would be paid $10.76 per hour for 41 hours each week. However, the plan reduced Therma's hours, even while her mother's Alzheimer's progressed. Thelma appealed the hour reduction with the MCO, and at the hearing, Thelma was up against a team from the MCO. MCOs come to hearings armed with an experienced team, including legal and medical experts, who know how to prevail over pro se beneficiaries and their families. Unfortunately, completely overwhelmed by the plan's defense, the hearing officer predictably sided with the plan's decision to reduce the number of hours. Prior to contacting FHJP, Thelma's hours were cut again in addition to terminating the seven meals provided per week.

Thelma again appealed the decision. This time, FHJP represented Hortense at an administrative hearing. After FHJP engaged in significant discovery the MCO agreed to reinstate her home delivered meals and personal care hours. As a result, Hortense is able to stay at home with her daughter and receives the care she desperately needs.

Reneged Hours for Paid Domestic Family Caregivers

Diwantie Campayne - Jacksonville, FL

Mankuar, 87, suffers from dementia and other chronic conditions, and was left wheelchair bound after she fractured her back. Her daughter, Diwantie, is caring for her mother 24/7 at home after her last discharge from a skilled nursing facility; however, the MCO had been uncooperative in providing the assistance and supplies needed to properly care for Mankuar safely at home. Diwantie was forced to leave her job to provide the care for her mother and the MCO initially offered to pay her 40 hours per week but has since reneged on that offer and only pays for 14 hours per week.

Diwantie contacted FHJP, which went on to represent her at an administrative hearing. During the litigation, the MCO offered her 40 hours per week of home health care aide and medically necessary supplies. As a result, Diwantie remains financially solvent while being able to fully care for her mother, rather than returning her mother to a skilled nursing facility.

Elevating Clients to the National Stage

FHJP client Alene Shaheed, a profoundly articulate and inspiring advocate, presented to Congressional staff and testified before the Senate Select Committee on Aging on the importance of HCBS. Following the loss of her mobility and being confined to a wheelchair, Alene requires the assistance of home health aides with activities of daily living in addition to homemaking services. But she often went days without any aides showing up to help. Alene understood that the underlying problem was extremely low pay for Medicaid home health workers and she spoke to the need for change.

> *"People in my situation should not have to spend another day alone in their wheelchair without a caregiver," Alene says. "We need funding and incentives to increase the pool of workers willing to provide care for Medicaid patients."*

After FHJP published Alene's story, she shared her experience in an article that appeared in The New York Times on November 1, 2021. FHJP worked with Alene and state and national partners in advocating for increased Medicaid HCBS funding—highlighting the need to pay higher wages to home health aides.

SIXT Period Termination

In late 2019, during the first year of Project Independence, Florida Medicaid eliminated the SIXT period, an important consumer protection which provided Medicaid LTC Waiver Program beneficiaries with a sixty-day grace period if there was a delay in the annual Medicaid renewal process. Under the SIXT period, the MCOs were required to continue providing HCBS for sixty days while the renewal issue was resolved with the state. Therese's story illustrates how these bureaucratic errors can result in termination of critical services and the import of a "grace period" for HCBS.

In March, 2020, before FHJP could begin assessing the impact of this policy change, the pandemic related moratorium on Medicaid terminations went into effect. While we anticipate that the state's implementation of an electronic verification process will reduce the number of terminations due to administrative errors, we also anticipate that there will continue to be instances where HCBS are terminated for a beneficiary while bureaucratic issues are resolved. FHJP has submitted public records requests for HCBS termination data since the moratorium on terminations was lifted in April 2023. FHJP will continue to advocate for the state to reinstitute the SIXT period in the LTC Waiver Program.

APPENDICES

Appendix 1: Praise for Advocate's Guide to the Florida Long-Term Care Medicaid Waiver

- I appreciated finding your publication @ https://www.ltcwaiver.org (the Advocates Guide to LTC...) It's the first document I've encountered that is informative and written for those involved in this nightmare journey of attempting to provide adequate, stable long-term home care for a loved one - namely my 95-year-old Mom - a stroke victim since mid 2019, legally blind and hearing impaired - yet quite cognitively capable, who wants to remain in her Leesburg, Florida home where she has lived for more than 20 yrs. One would think that FL DCF could not just drop a patient from services without prior notice, but that just happened on 07/01/2021and I was searching for answers, help, direction etc. when I came across this guide and just wanted to say thank you for your work & effort. - *Judy A.*

- THANK YOU THANK YOU THANK YOU!!! Just wish I found this resource two months ago when I started this process for my mother. I believe the state employees and Area Agency staff need to read this! *Comments found on ltcwaiver.org via Strikingly*

Appendix 2: Request for Correct Action on the template NABD

Regarding requested correct action: Include contact information for legal services programs on the template Notice of Adverse Benefit Determinations (NABD)

October 3, 2022

Dear Andrew,

We want to thank you and Kim again for taking the time on 9/29/22 to discuss our request that Notices of Adverse Benefit Determination (ABDs) be amended to include a link to a listing of local legal aid contact info.

Thank you also for agreeing to share the bullets below with Agency decision makers and your willingness to urge that AHCA make a decision within the next 2 weeks. (Noting that the issue and request have been pending for over a year. *see e.g.* emails: January 10, 2022, February 2, 2022, March 4, 2022, and March 30, 2022; April 8, 2022, September 9, 19, 2022; *see also* LTC renewal request comment letter on September 16, 2021; June 3, 2022 RFI letter regarding reprocurement.

ISSUE UNDERLYING NEED FOR CORRECTIVE ACTION:
Inability to ensure compliance with Medicaid law/AHCA contracts and inability of enrollee/ family members to adequately advocate for their rights.

While it goes without saying that AHCA staff are working incredibly hard to fulfill the mission of the Medicaid program and many go above and beyond in terms of public service on behalf of vulnerable beneficiaries, it is unrealistic to expect that AHCA (or any state Medicaid agency) will ever have sufficient resources to fully monitor the LTC Waiver plans. The relatively small number of clients assisted by FHJP and a few other advocates (see e.g. blog from Nancy Wright) represent the "a tiny tip of the iceberg."

SUMMARY OF NEED FOR CORRECTIVE ACTION:

- **Few people seek free legal assistance**. Our review of 163 LTC Medicaid Fair Hearing decisions showed that only 4 individuals (less than 3 %) of petitioners were represented by counsel.
- **Petitioners need legal counsel for a reasonable chance for success**. Of the 163 cases, those petitioners who had legal counsel had a success rate of 50%. The remaining 159 petitioners who were not represented only had partial success in 26% of cases. Most petitioners appeal pro se, which puts them at a distinct disadvantage in the hearing, e.g. ability to present witnesses, evidence, chance of settlement.
- **Witnesses:** Plans appear with an average of 4 witnesses, including e.g. medical directors, case managers, supervisors, and attorneys. By contrast, enrollees appear with no one or one (1) witness.

- **Evidence:** Plans on average submit 125 pages of evidence while enrollees submit, on average, 0 pages.
- **Pro se appeals are problematic:** As noted in the January 15, 2021 hearing on the unauthorized practice of law, pro se appeals create issues at the DCA and cause unrepresented litigants to bog down AHCA with questions that AHCA is limited in answering.
- **Settlement:** It is highly unlikely that legal aid attorneys will undertake representation unless the case has some merit, and it is also highly likely that disputed issues with merit will be resolved prior to an actual hearing IF the petitioner is represented. FHJP's own experience exemplifies this as all of our cases have been resolved prior to the hearing. see, e.g. examples of cases shared on our website here.
- **Precedent for including link to legal aid:** DCF's Notice of Case Action includes a link (albeit outdated) to legal services and this language: "*Free legal services are available at floridalawhelp.org*." (Note: the correct link is https://thefloridabarfoundation.org/florida-legal-aid-programs/.)
- **Cost/benefit:** While there would be some additional front end administrative cost if recipients knew of their right to seek free legal counsel because more hearings would be requested, it could actually lead to a decrease in the number of hearings held. *See* settlement bullet above. Moreover, the benefits of helping to ensure that recipients receive medically necessary care and that disputed decisions are resolved prior to a hearing is beneficial for all parties, including AHCA.

Current opportunity: The procurement process is a good opportunity for AHCA to implement this corrective action and require that the plans pay for any increased cost to the Agency in terms of increased number of hearings. e.g.

- See link to our comment letter regarding reprocurement.

Conclusion: in sum, the contact information for legal services on NABDs would not only be beneficial for enrollees and help address the lack of monitoring and transparency in the program, it would likely lead to a decrease in the need for fair hearings. The increased participation of legal aid attorneys would likely end up in more pre-hearing settlements, and thus eliminate the need for a hearing while mitigating the harm caused when plans improperly deny, reduce or terminate services. At a minimum, including a link to legal aid on ABDs would be a low cost action which AHCA can implement that would mitigate the underlying issue.

AHCA'S PRIOR REASONS FOR NOT APPROVING REQUEST "AT THIS TIME" AND FHJP'S "REBUTTAL": As noted in prior email, Kim had conveyed in our July 7 meeting that AHCA was not willing to grant our request "at this time." She cited two concerns that were raised in AHCA's internal discussion. Both concerns are listed below, along with FHJP's responses addressing the concerns.

AHCA's first concern: There are too many different legal services programs and the plans would not know who to put on the notice.

- *FHJP response:* There is a single website that lists all the legal aid programs in the state. A link to this website could easily be included in the NABD. https://thefloridabarfoundation.org/florida-legal-aid-programs/

AHCA's second concern: The Agency was concerned that including legal services contact information would appear as a "recommendation from the agency" that the person should contact legal aid.

- *FHJP's response*: These notices are not sent by AHCA; rather they are sent by individual plans in the template NABD. Additionally, there is long standing precedent in Florida in which DCF includes contact information for free legal aid services clients may wish to pursue. Indeed, after including the statement "*Free legal services are available at floridalawhelp.org,*." the DCF notices goes on to state: " *[i]f you need information about how to receive free legal advice, you can call the ACCESS Florida Customer Call center …..for a listing of free legal agencies in your area.*"

Appendix3: Demand Letter to AHCA Acting General Counsel

To: Andrew Shereen, AHCA Acting General Counsel
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Kim A. Kellum, Medicaid Chief Counsel kim.kellum@ahca.myflorida.com

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Date: January 23, 2023

Re: ***Alfonso Hernandez v. Humana***, AHCA Case No.: 22-FH1160

This letter is being sent on behalf of Alfonso Hernandez, an enrollee in AHCA's SMMC Long-Term Care Program Waiver. Mr. Hernandez's managed care plan is Humana. Mr. Hernandez is 99 years old and lives in his own home with his wife, who is also a Humana member under the LTC Waiver. He has been diagnosed with dementia, emphysema (on oxygen 24/7), glaucoma, peripheral vascular disease, and a host of other medical conditions. He is unable to transfer or walk, is incontinent, and requires extensive assistance with his ADLs and IADLs. His wife is similarly disabled and was authorized to receive 24/7 direct care in late 2021. At the time, Mr. Hernandez, however, was only authorized for 14 hours/week of Personal Care and 12 hours/week of Homemaker. Some home health aides for Mrs. Hernandez have been willing to assist with care for Mr. Hernandez, but other aides have pointed out correctly that they are not authorized nor paid to care for Mr. Hernandez and have refused to do so. In addition, when Mrs.

Hernandez is not in the home (for physician visits or hospitalization, for instance), no one is present to care for Mr. Hernandez.

For over a year, Mr. Hernandez's counsel, Nancy Wright, has been communicating with AHCA about this situation. After repeated oral requests to the Humana case manager went unanswered, in January of 2022, a written request was submitted to Humana seeking either 24/7 direct care services for Mr. Hernandez or, in lieu of this, sharing an aide. She filed an AHCA Complaint (Complaint # 2022-0224-0007) to force a response after Humana ignored the written requests for services. In the Notice of Adverse Benefit Determination ("NABD"), Humana approved only 16 additional hours/week of Personal Care and did not address the shared aide request in any way. A written appeal followed, making the same request. The Notice of Plan Appeal Resolution ("NPAR") was a denial, again failing to mention the shared aide request. Both Notices stated that a reason for the denial was based, in part, on the grounds that Mr. Hernandez's son helped care for him while recognizing that he also worked full-time outside the home.

The NABD also recommended Adult Day Care or Companion services, but the appeal pointed out that neither of these services were appropriate options for Mr. Hernandez who has a consistent need for hands-on care, an assertion supported by Mr. Hernandez's primary care physician. Mr. Hernandez requested a fair hearing on both the denial of Personal Care and the failure to address sharing an aide as an option.

The hearing revealed a host of problems with Humana's decision-making and a complete lack of understanding of the Long-Term Care Program Coverage Policy. For example:

- Humana stipulated that it did not have a Long-Term Care Supplemental Assessment for Mr. Hernandez nor did it have any documents or policies from AHCA or internal to Humana regarding the authorization and payment of direct care staff to provide supervision and care to more than one enrollee at a time.
- The Humana Medical Director was unfamiliar with the LTC Coverage Policy, referring instead to the Member Handbook as authoritative. She was unaware of the goal of the program, ["to provide an array of home and community-based services that enable enrollees to live in the community and to avoid institutionalization"], and could not explain what this meant even after it was read to her.
- She was unaware that the LTC Supplement Assessment was a separate assessment from the 701B and did not know what it was for. She made her decision assuming that Mr. Hernandez's son could provide physical care when he had made it clear to the Humana case manager that he could not. She also testified that Mr. Hernandez could "safely be left alone" for 18 hours a day by taking the daily allotment of 6 hours and splitting it into 3 or 4 shifts per day. In addition, she factored into her decision that Mr. Hernandez is "not a wanderer" and there were others in the household - paid help for Mrs. Hernandez - if needed.
- The Medical Director testified several times that her decision to provide only an additional 4 hours a day of Personal Care was made by estimating about 20 minutes per 3 day for each ADL and adding a couple more hours because of Mr.

Hernandez's "dementia and other medical needs." She admitted that Companion providers are not licensed for hands-on care but thought they could provide some incidental hands-on help.

Humana's failures might have been corrected through AHCA's fair hearing system. Unfortunately, they were overtly sanctioned or ignored by AHCA's Hearing Officer. These and other issues impacting due process included:

- The Hearing Officer stated at the hearing that she could not consider any argument on the request for a shared aide because "this has not been mentioned in the Notice of Plan Appeal Resolution and it's not an issue I have jurisdiction over."
- The Final Order never mentions the lack of a LTC Supplemental Assessment.
- The Final Order justifies Humana's decision to authorize Personal Care hours using minutes for ADLs by citing a table of "General Time Allowances" for Personal Care Tasks that is in the Personal Care Services Coverage Policy (Rule 59G-4.215). This is inconsistent with the goal of the LTC Waiver.
- Although the Hearing Officer was made aware of the licensing limitations for Companion in §400.462(7), Fla. Stat., the Final Order suggests the use of Companion care for "supervision" of Mr. Hernandez instead of Personal Care despite the extensive hands-on care needs of Mr. Hernandez round the clock. In any event, no decision was made on the appropriate array of services Mr. Hernandez needs to enable him to remain in his home and avoid institutionalization even though this decision was de novo and final agency action by AHCA.

Mr. Hernandez's difficulties with Humana, including ignored verbal requests for services, have been the subject of AHCA Complaints and quite a few emails and phone calls to AHCA's General Counsel Office. The hearing itself, however, revealed a level of ignorance of the rules surrounding the LTC Waiver that effectively nullify our settlement in *Parrales v. Dudek*, 4:15-cv424-RH/CAS. In the *Parrales* settlement, AHCA agreed to adopt the LTC Waiver Coverage Policy to protect enrollees from the arbitrary decisions that were coming from managed care plans. LTC Waiver enrollees like Mr. Hernandez continue to remain at risk of institutionalization if the managed care plans do not follow the rules and AHCA does not enforce them. If, for example, a managed care plan can limit the issues to be considered at a fair hearing by ignoring a request for a benefit or service in the NABD, despite evidence that the request had been made in writing, there is a fundamental due process issue in the way AHCA is conducting these hearings.

The disregard of the LTC Supplemental Assessment is not just a failure to fill out a form. Humana made its decision for LTC services for Mr. Hernandez by assuming that "natural supports" could or would provide care, which was incorrect, and by relying on the kindness of strangers - paid aides for the wife who were put in the awkward position of also providing voluntary service for Mr. Hernandez. This is not new, unfortunately. In our representation of numerous clients who require additional home health hours, we have found that individuals are routinely denied authorization of care hours based on the presence of others in their home without consideration as to whether the other people are willing or able to provide care voluntarily and unpaid. Denying authorization of home health hours based on the presence of others in the home who have not affirmatively

agreed to provide care voluntarily, is not consistent with the federal Medicaid Act, including the regulations that govern home and community-based service programs. The LTC Supplemental Assessment form is required by regulation to ensure that an accurate evaluation is made of the amount of time the enrollee can be safely left alone and the ability and willingness of natural supports to assist with the enrollee's needs. Failure to complete and consider the information collected in this form results in a failure to accommodate the needs of enrollees and places them at risk of institutionalization.

The decision on Personal Care is equally troubling. Personal Care is the only type of licensed direct care provider under the LTC Waiver that is authorized by law to give hands-on care. Any system that does not consider consistent hands-on care needs will result in inadequate care. As in this case, the "count the minutes" method encourages managed care plan to leave enrollees who need hands-on care throughout the day and night with staff who are not authorized to provide the very assistance that is needed. This policy is even more nonsensical when the pay structure is considered; on information and belief, managed care plans provide the same pay rate for Personal Care, Companion, and Homemaker services. One can only conclude that the system is designed to delay authorization of appropriate services by penalizing enrollees who request the "wrong" service. Rather than looking holistically at requests, or even asking questions about them, denials are issued, which AHCA Office of Fair Hearings uphold, sometimes with the suggestion that the enrollee try again. In the meantime, many months have passed without adequate care and it may take months more to get a different service approved, assuming the enrollee even knows to ask. All of this leaves enrollees at risk of institutionalization and runs afoul of the requirement that Medicaid services be provided with reasonable promptness.

Our Demand:

- Authorize 24/7 Personal Care for Mr. Hernandez.
- Develop a written protocol for how enrollees can request shared aides, and the criteria for managed care plans to authorize shared aides.
- Train case managers, supervisors, medical directors, staff attorneys, and AHCA hearing officers in the LTC Coverage Policy, including
    - the goal of program,
    - what "natural support" is
    - how and why LTC Supplement Assessment must be used
    - the need for written consent by natural supports for specific amount, duration and scope of care they consent to voluntarily providing.
- Sanctions for failure to have updated, signed LTC supplement assessment in case file.
- Provide a clear process for enrollees to submit written requests for services.
- Include a contract provision with managed care plans that they are required to treat requests for Homemaker, Companion and Personal Care as a request for direct care services and require that they issue authorizations that are an appropriate array of services. If a managed care plan fails to do this, provide for sanctions, and

train and direct Hearing Officers to reach decisions on the appropriate direct care service array rather than piecemeal decisions on a single service.

We look forward to speaking to you further about this matter. However, if we do not hear from you in two weeks or we are unable to resolve this within a month, we will advise our client to pursue federal options, including a preliminary injunction.

Sincerely,

/s/Nancy E. Wright Nancy E. Wright, Esq.

Attachments:

Request for Services
Physician Letter

Appendix 4: The New York Times | Biden Promised to Fix Home Care for Seniors. Much More Help May Be Needed

The New York Times

Biden Promised to Fix Home Care for Seniors. Much More Help May Be Needed.

By Reed Abelson Nov. 1, 2021

The latest Democratic proposal would funnel $150 billion toward subsidized home and community-based care. Experts worry that may not be enough to ease the severe shortage of workers.

Alene Shaheed of Jacksonville, Fla., who moves around in a wheelchair, saw her support system fall apart during the coronavirus pandemic this year. Credit...Agnes Lopez for The New York Times

Spinal surgery four years ago left Alene Shaheed in a wheelchair and dependent on short daily visits from home health aides to help her get around.

But her support system fell apart this year during the prolonged coronavirus pandemic, and her routine care became unpredictable. Four agencies serving her hometown, Jacksonville, Fla., failed to provide aides regularly, due to severe shortages of the low-wage workers.

“If no one comes for three days, I don’t get a bath for three days,” said the 76-year-old. “I don’t have anyone to fix meals, so I’m eating ramen noodles until someone gets there.”
About 800,000 people are on waiting lists to receive subsidized home care. For millions of Americans, finding reliable and affordable assistance to stay at home — instead of moving into a nursing home, where Covid-19 killed tens of thousands of people — has never seemed more urgent.

Expanding home and community-based services is part of the legislative package that President Biden and Democrats have proposed. At this stage of negotiations in Congress, the amount for such programs under Medicaid — partly to increase the historically low wages of home care workers — has been reduced to $150 billion from $400 billion over eight years.

“We’re going to expand services for seniors so families can get help from well-trained, well-paid professionals to help them take care of their parents at home — to cook a meal for them, to get their groceries for them, to help them get around, to help them live in their own home with the dignity they deserve to be afforded,” Mr. Biden said on Thursday.

Will the amount in the current plan be enough? Supporters say the new health care money would shift Medicaid’s decades-long bias away from nursing home care. Many experts doubt promises that this round of funding can fix a system as broken as home care, especially as the growing retirement of the boomer generation requires more assistance to stay independent and strains health care funding.

“You have to be very realistic about the amount of need you have in the system right now,” said David Grabowski, a professor of health care policy at Harvard Medical School. The $150 billion does represent a significant influx of funds, but there are limits, he said: “Once you start to do the math, the dollars don’t go as far as you’d like.”
States are required to use Medicaid funds to cover nursing home care, but states have considerable leeway under federal regulations to decide how much should be allocated to provide home and community-based services.

People who need help with tasks like feeding themselves, getting dressed or taking medication must often qualify for a Medicaid waiver to get home care. Medicaid, a federal-state program that is the primary source of coverage for long-term care, spends about $114 billion a year on these home and community-based services, representing well over half of the overall spending on long-term care. About 2.5 million people received waivers in 2018, according to the latest data available in a report by the Kaiser Family Foundation.

Medicare, the federal insurance program for older and disabled adults, does not cover long-term care and it limits the kind of home care people can receive. It's well known that demand far outstrips supply for home care for those who want to live independently. Some people may have private insurance or pay for the care themselves.

Under Medicaid, the waiting lists for older and disabled Americans wanting home care keep growing because states cap enrollment. Most people on the lists live in states that did not expand Medicaid, according to a Kaiser analysis.

Benefits for home care also vary widely from state to state. For example, someone in Pennsylvania is eligible for about $50,000 a year under Medicaid for home or community services, while someone in Iowa may get only $21,000.

The lack of funding "really forces older adults into institutions," said Amber Christ, an attorney with Justice in Aging, a nonprofit group. The new congressional package, she said, means that "we have an opportunity to flip the script."

She and other advocates plan to push for additional money. "We're going to keep working to increase funding because more is needed to ensure all aging adults and people with disabilities have the option to receive the care they need at home," she said in an email.

Increasing wages for home health workers has been a contentious provision for Republicans, who see it as a giveaway to unions and would limit states' flexibility in spending new funds. Without detailed legislative language, calculating how the proposed $150 billion in the Democrats' proposal will be spent is still guesswork.

Jonathan Gruber, a health economist at M.I.T., said the lower figure would provide home services for perhaps one million more people and create about 400,000 new jobs. That could include jobs for caretakers like family members who are unpaid but unable to go to work.

But if the amount gets cut further — and negotiations on the bill are far from over — supporters warn that states may be less willing to expand services. "We need a big investment," said Nicole T. Jorwic, senior director of public policy at The Arc, an advocacy group for people with physical and developmental disabilities. The bill has to provide at least $150 billion so "states will see the value and worth of taking it up," she said.

Even that level of funding might not eliminate the waiting lists, but "it will help take people off," she said.

Under the American Rescue Plan Act passed by Congress this year, all states made use of temporary funds allocated to shore up home and community-based services, Ms. Jorwic said. Still, the issue of wages in a pandemic economy where people are shunning lower-rung jobs bodes ill for the home health industry, whose workers have long been paid far less than others in service industries. Some businesses now pay $15 an hour or

more, luring away those in underpaying jobs and leaving the vulnerable without reliable help.

About 70 percent of long-term care workers earn less than $30,000 a year, according to Kaiser, and they are more likely to live in poverty. “It’s the same person who is aging into poverty and who is going to get pushed into a nursing home,” said Ms. Christ of Justice in Aging.

While details are sparse, the proposed legislation would require states to prove that the funds were funneled toward higher wages. “This would be the first time that there was a large federal investment to increase wages,” Ms. Jorwic said.

Higher wages are critical to finding more aides for those like Ms. Shaheed in Florida. “They’re no longer able to find anyone willing to come in for the low wages they are paying,” she said. “Nobody is going to come and help me for $10 an hour.” For those who have had to wait to qualify for financial aid for home care, the difference is palpable.

People like Stephen Grammer, who has cerebral palsy, were warned since childhood that they faced institutionalization if home care could not be routinely provided. In his 20s, Mr. Grammer spent nearly a decade in a nursing home after his mother became ill. He chafed at the restrictions imposed on him while he was living with older adults with Alzheimer’s. If he left the premises, he had to be back by midnight or it would count against the 18 nights a year he was allowed to be outside. “When I had to use the restroom, I would press the call button, and many times the workers would come and turn off my call light and would walk away even though I had to go to the bathroom,” he said by email.

Mr. Grammer, who uses an electric wheelchair and advocates for disabled individuals these days, eventually qualified for a Medicaid waiver and another state program that provides housing. Now at 41, he lives on his own in Roanoke, Va., and someone comes in 16 hours a day from 6 a.m. to 2 p.m. and from 4 p.m. to midnight. “I have the freedom to come and go as I please,” Mr. Grammer said.

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