

IN THE SUPREME COURT OF FLORIDA

**IN RE: AMENDMENT TO THE
RULES REGULATING THE
FLORIDA BAR - MISCELLANEOUS**

CASE NO. SC2022-1292

COMMENT BY THE FLORIDA HEALTH JUSTICE PROJECT

I. Introduction

Florida Health Justice Project (FHJP) is a non-profit organization which engages in comprehensive advocacy, including legal advocacy, to expand healthcare access and promote health equity for vulnerable Floridians, including children, people with disabilities, and seniors. We are profoundly grateful for the Florida Bar Foundation's financial support of this work.

FHJP was founded in late 2017 because Florida needed a statewide poverty health law program.¹ As FHJP enters its sixth year serving in that role, it has never been clearer that the need for free health law assistance far outpaces the supply of Florida's poverty health lawyers. This comment letter summarizes the unmet

¹ See Harmatz and DeBriere, *Statewide Poverty Health Law Programs: Necessary to a Legal Aid Delivery System*, Management Innovation Excellence for Legal Aid Journal (M.I.E. Journal), Spring 2021 article, accessible at: https://www.floridahealthjustice.org/uploads/1/1/5/5/115598329/2021_spring_journal_final.pdf.

need and how enhanced IOTA funding would enable FHJP to address those needs.

II. Helping Floridians terminated from Medicaid coverage.

A. The unmet need

After the pandemic-related Medicaid continuous coverage requirement ended on March 31, 2023, Florida's Department of Children and Families (DCF) began redetermining the eligibility of approximately 5 million Floridians and sending termination notices to those deemed no longer Medicaid eligible or who failed to complete their renewal within 30 days. This 12-month redetermination process is also referred to as the "unwind."

In anticipation of the unwind, FHJP's Advocacy Director spent much of 2021-22 creating and disseminating multiple tools for advocates and consumers to help identify and refer members of at-risk populations and mitigate coverage loss. We also created a dedicated "PHE unwind" website so that individuals impacted could easily access our self-help materials.²

² FHJP's PHE unwind website is accessible at:
<https://www.floridahealthjustice.org/ending-continuous-medicaid-coverage.html>.

The unmet legal needs of Florida Medicaid beneficiaries during the PHE unwind are enormous. In the first 5 months, approximately 730,000 low-income Floridians have been terminated from Medicaid, and a number of legal problems have been documented.³

Among other issues, Florida's termination notices are extremely confusing and lack adequate explanation about the agency's action; many are clearly erroneous, and virtually no one is aware of their right to appeal or how to do so. That is why, in August 2023, FHJP and the National Health Law Program (NHeLP) filed a federal lawsuit challenging these inadequate notices in *Chianne D., et al v. Weida, et al.*, Case No. 3:23-cv-985 (M.D. Fla.).⁴

B. What We Can Achieve with Increased Funding

From the cohort of self-referred individuals, we have identified several populations being improperly terminated. This includes new

³ As of October 23, 2023, 99 clients have contacted FHJP for advice or assistance on their Medicaid terminations with the vast majority being self-referrals.

⁴ See FHJP's press release about the case accessible at: <https://www.floridahealthjustice.org/publications--media/press-release-suit-challenges-florida-over-illegal-medicaid-terminations-marking-first-lawsuit-amid-chaotic-nationwide-medicaid-unwinding>.

moms within the 12 months of postpartum coverage,⁵ elderly and disabled eligible for Medicaid Savings Programs,⁶ and/or home and community-based services (HCBS).⁷ Additionally, youth that are age 19-20 may remain eligible for Medicaid if they knew to apply as a household of one. However, DCF has failed to provide policy guidance regarding this eligibility category and staff incorrectly advise youth not to apply. While we have assisted several clients in each of these groups and have some data on the impact (over 56,000 19–20-year-olds have been terminated), we have not had the funding and resources to investigate potential underlying systemic issues and pursue affirmative advocacy.

Current funding restrictions also limit our capacity to provide representation in complex Medicaid termination appeals involving disability claims. With few exceptions,⁸ FHJP does not have the

⁵ See “Lindsey’s Story” accessible at:
<https://archive2.floridahealthstories.org/lindsey>.

⁶ See “Melissa B.’s Story” accessible at:
<https://archive2.floridahealthstories.org/melissa-b>.

⁷ See “Michael W.’s Story” accessible at:
<https://archive2.floridahealthstories.org/michael-w>.

⁸ See “Dylan’s Story” accessible at:
<https://archive2.floridahealthstories.org/dylan>.

resources necessary to provide direct representation for individuals who contact us about an erroneous termination. Additional resources would enable us to build our capacity to handle individual cases directly as well as build on our self-help resources and establish a pro bono network.

III. Helping Floridians with Disabilities Access Long-Term Care Services.

A. The Unmet Need

Since the founding of our organization, FHJP has prioritized helping low-income seniors and persons with disabilities enrolled in Florida's Long-Term Care (LTC) Medicaid waiver. This program provides home and community-based services (HCBS) to a limited number of Floridians who require a nursing home level of care. Over the last five years, FHJP has spent considerable time creating tools, including a comprehensive advocate's guide (now in its 5th edition),⁹ as well providing training sessions and technical assistance. We have also engaged in significant administrative advocacy.

⁹ See The Advocate's Guide to the Florida Long-Term Care Medicaid Waiver, Florida Health Justice Project (July 2022), accessible at: <https://www.floridahealthjustice.org/advocates-guide-to-the-florida-long-term-care-medicaid-waiver.html>.

Once an individual is enrolled in the LTC waiver, a plan of care is developed. Under governing authority, this plan should authorize the specific services required for the enrollee's daily health and support needs and include information on appeal rights. Unfortunately, these plans often fail to do so for the approximately 100,000 current enrollees. In 2023, Florida ranked 43rd in spending on long term supports and services and 50th in support for family caregivers.¹⁰ Unsurprisingly, then, FHJP consistently receives requests for assistance¹¹ in securing needed supports and services through the LTC Waiver.

When services on the LTC Waiver are denied, reduced, or terminated, enrollees have the right to appeal that action to the Office of Fair Hearings at the Agency for Health Care Administration (AHCA). FHJP reviewed 163 LTC Waiver Medicaid Fair Hearing decisions¹² held between June 2020 and June 2021. The key findings

¹⁰ See AARP, *LTSS 2023 State Scorecard Report on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, Florida, accessible at: <https://ltsschoices.aarp.org/scorecard-report/2023/states/florida>.

¹¹ FHJP STORIES, Long-Term Care, accessible at: <https://www.floridahealthstories.org/long-term-care>.

¹² FHJP, Review of Medicaid Managed Care Long Term Care (LTC) Hearings (June 13, 2023), accessible at:

were that an extremely small number of beneficiaries had legal counsel (only 4 out of 163, or 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. Most beneficiaries who lacked legal counsel presented no evidence and had no witnesses. By contrast, enrollees who were represented by an attorney presented witnesses and submitted documentary evidence. Indeed, FHJP has found that even filing a notice of representation and discovery is helpful to bringing about a positive resolution.

B. What We Can Achieve with Increased Funding

FHJP's three practicing attorneys handle all direct representation matters, as well as participating in FHJP's impact litigation and other activities that support our case work and mission. This leaves insufficient capacity to handle individual cases, including Medicaid Fair Hearings. With increased funding, FHJP could create a legal unit dedicated to representing Seniors & People

<https://www.floridahealthjustice.org/publications--media/review-of-medicaid-managed-care-long-term-care-ltc-hearings>.

with Disabilities.¹³ This unit would include at least one attorney and paralegal responsible for handling multiple individual LTC Waiver Fair Hearings, as well as providing support to pro bono and other legal aid attorneys wishing to handle these cases.

IV. Helping Florida’s Seniors Improperly Discharged from Skilled Nursing Facilities (SNFs)

A. The Unmet Need

Individuals residing in skilled nursing facilities can only be discharged for a finite set of reasons.¹⁴ When a nursing facility discharges an individual, the resident is entitled to written notice and a hearing to challenge the discharge. If appealed timely, the individual can continue to live in the nursing facility until a final hearing decision is reached. In 2022, the Florida Long-Term Care Ombudsman Program received 35,000 discharge notices.

For those without representation, the outcomes of their appeals of discharge are grim. FHJP conducted a review of final

¹³ With increased IOTA funding our strategic plan is to organize legal case work into three units. The other two units would focus on Low-Income Children & Maternal Health, and the Uninsured.

¹⁴FHJP, *Defending Evictions From Florida Nursing Facilities*, accessible at: https://www.floridahealthjustice.org/uploads/1/1/5/5/115598329/defending_evictions_from_florida_nursing_facilities_december_2022.pdf.

discharge orders. As many of these final orders were heavily redacted, specific data regarding representation is difficult to determine. However, we gleaned the following data: 125 residents either represented themselves as pro se petitioners (51) or were represented by a family member (52). Only four residents were represented by an attorney and six were represented by an ombudsman. In two instances, both a family member and an ombudsman represented the resident during the hearing.

There were two orders that only indicated that the resident had a “representative,” one that listed “health care proxy” as the representative, one that listed “power of attorney,” and nine where it is unclear whether there was any representation. The success rate for the very few with representation was more than double that for those who lacked representation.

B. What We Can Achieve with Increased Funding

As with the LTC Waiver cases, FHJP’s Senior unit could hire an attorney dedicated to representing nursing home residents in their discharge appeals. While one attorney will not be enough to meet the needs of all Florida residents being discharged from their nursing home placement, FHJP would use this position to develop and share

resources with legal aid organizations also handling these cases and build a pro bono network of attorneys willing to do the same. FHJP has a strong history in successfully developing resources and providing CLE-approved training. In addition to the LTC Advocate’s Guide, we recently published a *pro se* guide to Medicaid appeals with DCF’s OAH¹⁵ and we have already published multiple resources regarding the rights of nursing facility residents, *see e.g.*, “Know Your Rights: Avoiding Misuse of Psychotropics for Nursing Home Residents”¹⁶ and “Transition from a Florida Nursing Facility into the Community.”¹⁷

V. Helping Florida’s Low-Income Children: Early and Periodic Screening, Diagnosis and Treatment Services (EPSDT) Appeals

A. The Unmet Need

¹⁵ FHJP, Florida Medicaid Appeals Toolkit – 1st Edition (October 9, 2023), accessible at: <https://www.floridahealthjustice.org/publications--media/florida-medicaid-appeals-toolkit-1st-edition>.

¹⁶ FHJP, *Know Your Rights: Avoiding Misuse of Psychotropics for Nursing Home Residents* (March 27, 2023), accessible at: <https://www.floridahealthjustice.org/publications--media/know-your-rights-avoiding-misuse-of-psychotropics-for-nursing-home-residents>.

¹⁷ FHJP, *Right to Home/Community Placement for Nursing Home Residents* (September 7, 2022), accessible at: <https://www.floridahealthjustice.org/publications--media/fhjp-snf-to-ltc-waiver-handout>.

Under the federal Medicaid Act, children enrolled in Medicaid are entitled to a special protection known as EPSDT which includes a requirement that states must provide *all* Medicaid-covered services necessary to “correct or ameliorate” physical or mental conditions of Medicaid beneficiaries under age 21. A service will “correct or ameliorate” a child’s condition if it corrects, compensates for, improves or prevents a condition from worsening, even if the condition cannot be prevented or cured.

Our pending class action, *W.B. v. Weida*, No. 3:21-cv-771-MMH-PDB (M.D. Fla.),¹⁸ challenges the standard AHCA relies on¹⁹ to determine whether Medicaid services are medically necessary for children under age 21. Through discovery, FHJP had the opportunity to review 226 total fair hearing orders issued in 2021. The hearings involved a range of service requests including: orthodontia, specialty medical equipment, behavioral health services, and medical daycare. Similar to LTC Waiver and SNF

¹⁸A copy of the complaint filed in this matter is accessible at: https://www.floridahealthjustice.org/uploads/1/1/5/5/115598329/w.b._complaint_filed.pdf.

¹⁹ FHJP, *The Right to Medically Necessary Treatment for Florida’s Children*, accessible at: https://uploads.strikinglycdn.com/files/ddf106c4-83de-4f5a-8190-5777db6f83a3/epsdt_factsheet_issue_brief_final_-1.pdf.

discharge hearings, the majority of petitioners went unrepresented (or, in this instance, because they are children, they were represented by a parent or caregiver). In total, 184 caregivers represented the child in the Fair Hearing, 35 providers acted as a representative, and six were self-represented. Of the 226 cases reviewed, only one individual in need of services was represented by legal counsel.

Of the 226 outcomes reviewed, only 29 total petitioners won their case, with a reversal of the decision to deny, reduce, or terminate a Medicaid service (in one of those cases, the reversal was only partial). Thus, children fighting for EPSDT services before the AHCA Office of Fair Hearings had a meager success rate of only about 13%. The vast majority of those cases (19/29 or 66%) involved parents or other caregivers representing their child -- navigating a confusing appeal system and preparing for a high-stakes hearing while also taking care of a child with unmet medical needs and managing a low-income household.

Through our *W.B.* litigation, FHJP agreed to bring putative class members (those children whose services were denied based on an unlawful standard of “medically necessary”) to AHCA’s attention

to redetermine whether the service denial, termination, or reduction was proper. From 2019 to 2023, FHJP brought eight children to AHCA's attention pursuant to this agreement. All eight children had their services approved upon AHCA's review. Of those children, two had previously gone through the entire fair hearing process without legal representation and lost at their fair hearings. One medically fragile child had been denied a specialty medical bed designed to keep her g-tube from wrapping around her neck while she slept at night. The other child, whose near drowning at age seven left him immobile and nonverbal, had been denied a wheelchair with features that allowed him to communicate with his eye-gaze and relieved needed pressure on his spine, particularly critical after a recent spinal surgery.

Notably, in January 2021, AHCA sought an opinion from the Florida Bar regarding whether parents and caregivers of children and incapacitated adults were authorized to represent Medicaid beneficiaries appealing fair hearing decisions to the state district courts of appeal. FHJP participated in the public hearing²⁰

²⁰ Nancy Kinnally, *Florida Bar Considers Whether Family Members Assisting Children and Incapacitated Adults in Medicaid Appeals are Engaging in Unlicensed Practice of Law* (January 21, 2021), accessible at:

regarding AHCA's request and strongly opposed a finding that parents and caregivers representing children and adults with disabilities on appeal constituted the unauthorized practice of law. Fortunately, the Florida Bar abstained from reaching an affirmative position. However, AHCA's request underscores the need for legal aid attorneys available to provide skilled representation both at the administrative and state appellate level.

B. What We Can Achieve with Increased Funding

FHJP envisions an entire legal unit dedicated to representing children in the Medicaid program in accessing needed medical services. FHJP's legal director has previous experience directing a pediatric medical-legal partnership (MLP) framework. Building on this experience and FHJP's existing relationships with specialty pediatric clinics around Florida, FHJP would use increased IOTA funding to hire one to two staff attorneys to provide training, technical assistance, and direct representation of these clinics' patients.

VI. Helping Pregnant Women in Florida Access Midwifery

<https://www.floridahealthjustice.org/publications--media/florida-bar-considers-whether-family-members-assisting-children-and-incapacitated-adults-in-medicaid-appeals-are-engaging-in-unlicensed-practice-of-law>.

A. The Unmet Need

Expansion of access to high quality and culturally sensitive midwifery care is a key tool in addressing the national maternal health crisis and its disproportionate impact on Black and Indigenous people.²¹ The midwife's holistic approach to prenatal and perinatal care has already proven effective in numerous states' efforts to address poor maternal health outcomes.²² Expanding Medicaid access to midwifery care has the potential to significantly improve Florida's maternal health outcomes.

From September 2019 to January 2020, FHJP undertook a secret shopper survey to assess access to midwifery care for Miami-Dade County (MDC) women covered by Medicaid. We were spurred to undertake this research after hearing from midwives about their challenges in meeting the needs of expectant mothers covered by Medicaid. With the 2021 maternal death rate of Black women more

²¹ P. Mimi Niles, Laurie C. Zephyrin, *How Expanding the Role of Midwives in U.S. Health Care Could Help Address the Maternal Health Crisis*, Commonwealth Fund (May 5, 2023).

²² Saraswathi Vedam, Kathrin Stoll, Marian MacDorman, et al., *Mapping Integration of Midwives Across the United States: Impact on Access, Equity, and Outcomes*, Plos One (February 21, 2018).

than 4 times higher than that of White women in Florida (95.6 and 22.1 per 100,000 live births, respectively),²³ the matter of access to midwifery care merits close attention. Our findings suggest that all of the county's Medicaid managed care organizations (MCOs), were violating provisions of their contracts with AHCA, including that: (1) the MCO must maintain an accurate and complete online provider directory; and (2) the MCO must maintain a region-wide network of providers in sufficient numbers to meet the network capacity and geographic access standards for services.

B. What We Can Achieve with Increased Funding

While we have cultivated extensive relationships with midwives and maternal and infant health advocates around the state, we lack the capacity to take on individual cases of women unable to access midwifery care. With additional resources, we could hire an attorney focused on maternal healthcare access issues, including access to midwifery care. This work would include filing complaints on behalf of individual clients with the Medicaid Agency and grievances against the MCOs.

VII. Impact Litigation

²³ Florida Health Charts, *Maternal Deaths by Race*, (2021).

The vulnerable individuals described above need direct legal representation if they cannot get medically necessary services, or they are being discharged from a nursing facility. They need an attorney to ensure that precious Medicaid eligibility or access to services is obtained. With increased IOTA funding FHJP can accept far more cases for direct representation.

The ability to hire more attorneys and vastly expand our individual case load also impacts FHJP's systemic legal work.²⁴ FHJP has maintained a heavy docket of major cases throughout the past 5 years, with virtually all of the requisite work handled by our single legal director. We can maintain this docket due, primarily, to partnerships with tremendous national legal services organizations, including NHeLP. However, with only one attorney whose primary job is systemic litigation and no paralegal support, FHJP has been forced to forego important issues to focus on others. Additionally, many systemic issues are discovered and developed through individual representation. Through funding the proposed special units for FHJP's legal work, the organization would better be able to

²⁴ A description of FHJP's litigation docket and the relevant pleadings filed in those matters can be found at:

<https://www.floridahealthjustice.org/litigation.html>.

identify and address the systemic issues arising from direct client assistance.

VIII. Conclusion

Thank you for considering our comment. If you have any questions or require further information, please do not hesitate to contact us.

Dated: October 31, 2023

Respectfully submitted,

/s/Katy DeBriere

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CERTIFICATE OF TYPE SIZE AND STYLE

I certify that this petition is typed in 14-point Bookman Old Style type.

Respectfully submitted,

/s/Katy DeBriere

Legal Director
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CERTIFICATE OF SERVICE

I HEREBY CERTIFY that on this 31st day of October 2023, the foregoing was filed and served via the State of Florida’s e-filing portal to:

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Respectfully submitted,

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