

STATE OF FLORIDA
DIVISION OF ADMINISTRATIVE HEARINGS

CALEB JONES, by and through,
MARCIA BANKS JONES, and
DISABILITY RIGHTS FLORIDA

Petitioner,

vs.

Case No.

AGENCY FOR HEALTH CARE
ADMINISTRATION,

Respondent.

PETITION TO DETERMINE INVALIDITY OF RULE

I. Preliminary Statement

1. Petitioner, Caleb Jones, is a 19-year-old medically complex young adult whose care demands are significant. He is diagnosed with quadriplegic cerebral palsy, intellectual disability, muscle spasticity, and partial epilepsy. He uses a wheelchair for ambulation, requires a gastrostomy tube for nutrition, and has a ventriculoperitoneal (VP) shunt. Petitioner is enrolled in Medicaid which reimburses crucial medical services and supplies that he requires daily including, incontinence supplies.

2. When Petitioner turns 21 years old, however, his current Medicaid plan will no longer reimburse for certain medical services and supplies that are necessary to his health and well-being. To continue receiving these services, which enable Petitioner to live in the community instead of an institutional setting, Petitioner must be enrolled in a Medicaid home and community-based services waiver (HCBS) program.

3. Under HCBS Medicaid waivers programs, the participant number is capped, and enrollment is not offered unless a slot is available. As a result, these programs have extremely

lengthy waitlists. However, under Fla. Stat. §409.979(3)(f)(1), the Florida legislature has established criteria which allows individuals, like Petitioner to bypass the waitlist for Florida’s Statewide Medicaid Managed Care (SMMC) Long Term Care waiver program (hereinafter, the “LTC Waiver”). Specifically, the Legislature allows individuals to bypass the LTC Waiver waitlist if they have a chronic debilitating health condition that make them “dependent upon 24-hour-per-day medical, nursing, *or* health supervision *or* intervention”). *Id.* (emphasis added).

4. Unfortunately, and in violation of Chapter 120 of the Florida Statutes, Respondent, the Agency for Health Care Administration (AHCA or the Agency), relies on an unadopted rule which improperly narrows the criteria set forth in Fla. Stat. §409.979(3)(f)(1) and limits priority LTC Waiver enrollment to only those children aged 20 ½ years old who are enrolled in Medicaid and actively receive private duty nursing services. Specifically, the Agency statement that operates as an unadopted rule and which was applied to Petitioner when he was denied priority LTC Waiver enrollment is as follows:

Current Florida Medicaid recipients who meet certain requirements do not have to be screened for the Statewide Medicaid Managed Care (SMMC) Long-Term Care (LTC) program; these recipients include: *Persons who are receiving Florida Medicaid services, and...[a]re a child under age 21 already enrolled in Medicaid and getting private duty nursing services;¹ six (6) months before the child’s 21st birthday, the child’s MMA plan sends a referral to CARES to help transition the child to the SMMC LTC program.* (Emphasis added).

5. Petitioner is not yet 20 ½ and does not actively receive private duty nursing services so the Agency, through its managed care plan contractor, Children’s Medical Services (CMS), denied Petitioner’s request for priority enrollment into the LTC Waiver program even

¹ The Agency describes “private duty nursing services” as “medically necessary skilled nursing to recipients whose medical condition, illness, or injury requires the care to be delivered in their home or in the community.” Fla. Admin. Code R. 59G-4.261 (November 2016).

though he meets the criteria set forth in Fla. Stat. §409.979(3)(f)(1) (i.e., he is an 18-, 19-, or 20-year-old whose health condition requires 24-hour-per-day health supervision and intervention).

6. Therefore, pursuant to Fla. Stat. §120.56(1)(a) & (4), Petitioner, having been substantially affected by the Agency's statement that acts as an unadopted rule, seeks an administrative determination of the invalidity of the Agency's statement on the grounds that it is an invalid exercise of delegated legislative authority because it is an unadopted rule that modifies and contravenes the provisions of Fla. Stat. §409.979(3)(f)(1).

II. Parties

7. Petitioner, Caleb Jones, lives at 10713 Sandy Oaks Drive, Jacksonville, Florida 32221. Petitioner's mother and court appointed guardian is Marcia Banks Jones who resides at the same address as Petitioner.

8. The Agency for Health Care Administration, located at 2727 Mahan Drive, Tallahassee, Florida, 32308, is the agency affected by this Petition. The Agency is responsible for administering the SMMC LTC Waiver. *See* Fla. Stat. §409.978(1).

III. Disputed Issues of Material Fact

9. Petitioner is unsure of what facts, if any, the Agency will dispute but based on past representations to Petitioner's guardian, Petitioner anticipates that the Agency, on the reliance of its statement which acts as an unadopted rule, will dispute that Petitioner meets eligibility for priority enrollment on the LTC Waiver as described in Fla. Stat. §409.979(3)(f)(1).

IV. Ultimate Facts and Entitlement to Relief

A. Description of the LTC Waiver & Its Enrollment Process

10. Florida's LTC Waiver administered through the Agency's long-term managed care program is authorized by 42 U.S.C. §1396n(c). The LTC Waiver furnishes an array of

HCBS services to Medicaid beneficiaries, including services that promote community integration and deter institutionalization. These services include, among other things, consumable medical supplies, like incontinence supplies, and private duty nursing. These services are not available to Medicaid beneficiaries aged 21 and older unless they are also enrolled on the LTC Waiver. *See Fla. Admin. Code R. 59G-4.192.*

11. Fla. Stat. §409.979 governs LTC Waiver eligibility.

12. The LTC Waiver has limited capacity; therefore, immediate enrollment on the LTC Waiver is not guaranteed. Instead, individuals are prioritized for potential enrollment using a frailty-based screening tool that calculates and assigns a priority score. *See Fla. Stat. §409.979(3)(a).* As of November 29, 2021, there are approximately 55,260 individuals on the LTC Waiver enrollment waitlist awaiting enrollment and access to services.

13. When initiating an application for LTC Waiver services, most individuals are required to contact their regional Aging and Disability Resource Center (ADRC) and schedule an appointment to be screened for LTC Waiver eligibility and enrollment. Fla. Stat. §409.979(3)(a)(1)-(2)

14. While most individuals who apply for LTC Waiver services must undergo an ADRC administered assessment using the frailty-based screening tool and then are placed on the LTC Waiver waitlist, Fla. Stat. §409.979(3)(f) allows certain, prescribed individuals to bypass the screening and waitlist process and, instead, affords them priority LTC Waiver enrollment.

15. Specifically, Fla Stat. §409.979(3)(f)(1) provides that:

“the following individuals are afforded priority enrollment for home and community-based services through the long-term care managed care program [LTC Waiver] and do not have to complete the screening or wait-list process if all other long-term care managed care program eligibility requirements are met...[a]n individual who is 18, 19, or 20 years of age who has a chronic

debilitating disease or condition of one or more physiological or organ systems which generally make the individual dependent upon 24-hour-per-day medical, nursing, or health supervision or intervention.”

B. Description of the Agency’s Statement Governing Priority LTC Waiver Enrollment for Individuals 18, 19, or 20 as an Invalid Exercise of Delegated Legislative Authority.

16. In deciding whether a person should be afforded priority LTC Waiver enrollment pursuant to Fla. Stat. §409.979(3)(f)(1), the Agency relies on the following statement (hereinafter, “Agency’s statement” or “statement”):

Current Florida Medicaid recipients who meet certain requirements do not have to be screened for the Statewide Medicaid Managed Care (SMMC) Long-Term Care (LTC) program; these recipients include: *Persons who are receiving Florida Medicaid services, and...[a]re a child under age 21 already enrolled in Medicaid and getting private duty nursing services; six (6) months before the child’s 21st birthday, the child’s MMA plan sends a referral to CARES to help transition the child to the SMMC LTC program.* (emphasis added).

17. This statement can be found in the following places:

- a. The Agency’s website page which describes the process for applying to the Statewide Medicaid Managed Care Long-Term Care Program, including the LTC Waiver,²
- b. The Agency’s SMMC Model Health Plan Contract, Exhibit II-A, Section VI(E)(8)(b)(2), page 33-34,³
- c. The policies of the managed care plans⁴ that administer Medicaid on behalf of the Agency.

18. Nothing listed in paragraph 17 has been promulgated as a rule by AHCA.

² This webpage is accessible at: https://ahca.myflorida.com/Medicaid/statewide_mc/ltc_scrn.shtml#scrn_ex.

³ The AHCA SMMC Model Contract is accessible at: https://ahca.myflorida.com/medicaid/statewide_mc/pdf/Contracts/2021-10-01/Exhibit_II_A_MMA-2021-10-01.pdf.

⁴ Managed care plans are defined at Fla. Stat. §409.926(10).

19. This statement is a rule. The statement meets the definition of a “rule” because it is an agency statement of general applicability that implements, interprets, or prescribes the statutory law governing LTC Waiver eligibility and enrollment, and more specifically, the law governing when an individual may bypass the screening and waitlist process for the LTC Waiver. *See Fla. Stat. §120.52(15)*. It is generally applicable because it applies uniformly to a class of individuals over which Respondent exercises authority – namely, all individuals seeking to bypass the LTC Waiver screening and waitlist process and, instead, be afforded priority LTC Waiver enrollment.

20. This statement is invalid because it is an unpromulgated rule. The Agency has failed to follow applicable rulemaking procedures set forth in Fla. Stat. §120.54(1)-(3) prior to generally applying the statement to all individuals seeking priority enrollment, based on the criteria set forth in Fla. Stat. §409.979(3)(f)(1), in the LTC Waiver.

21. The statement is invalid because it acts as a rule that enlarges, modifies, and contravenes the specific provisions of law it purports to implement. Even if the Agency were to adopt the statement as a rule, the statement modifies and contravenes the specific statutory provisions it purports to implement by allowing only the following individuals to be considered for priority enrollment under Fla. Stat. §409.979(3)(f)(1):

- a. Individuals presently eligible for and receiving Florida Medicaid services,
- b. Who are 20 ½ years, *and*
- c. Who actively receive private duty nursing services.

In sum, the statement is invalid because it acts to exclude from LTC Waiver priority enrollment pursuant to Fla. Stat. §409.979(3)(f)(1) all 18-, 19-, and 20-year-old individuals who have a chronic debilitating disease or condition of one or more physiological or organ systems

which generally make the individual dependent upon 24-hour-per-day medical, nursing, or health supervision or intervention unless those individuals are also already enrolled in Medicaid, are age 20 ½ years, *and* actively receive private duty nursing services.

22. The statement is invalid because it is arbitrary and capricious. The Agency's statement is arbitrary because the decision to limit priority enrollment as described in Fla. Stat. §409.979(3)(f)(1) to only those individuals who are currently Medicaid enrolled, 20 ½ years old, and actively receiving private duty nursing is unsupported by logic and the necessary facts. The statement is capricious because the Agency relies on it without having provided thought or reason behind the decision to limit the group of medically complex children eligible for priority enrollment. The statement precludes a balanced consideration of the criteria in Fla. Stat. §409.979(3)(f)(1) in determining whether an individual is entitled to priority LTC Waiver enrollment.

23. The Agency received notice, via electronic mail from undersigned counsel, of the intention to challenge the Statement as an unadopted rule first on May 6, 2019, and as recently as March 25, 2021.

V. How Petitioners Are Substantially Affected

A. Petitioner Caleb Jones

24. Any person who is substantially affected by an unadopted rule can request that an Administrative Law Judge determine that the rule is an invalid exercise of delegated legislative authority pursuant to Fla. Stat. §§120.56(1) & (4). Petitioner, Caleb Jones, meets these criteria and has standing to bring this proceeding.

25. Petitioner is a 19-year-old medically complex young adult. Petitioner is enrolled in Florida's Medicaid program but is not enrolled in the LTC Waiver portion of the program.

26. Petitioner is diagnosed with quadriplegic cerebral palsy, intellectual disability, muscle spasticity, and partial epilepsy. He uses a wheelchair, requires a gastrostomy tube for nutrition, and has a VP shunt. Petitioner is fully dependent on his caregivers for all activities of daily living. He requires physical assistance with ambulation, bathing, dressing, eating, grooming, and toileting. Petitioner cannot be left alone; if he is, his health and safety would be seriously jeopardized.

27. Petitioner's primary care physician, Dr. Rita Nathawad, confirms that Petitioner is "[a]n individual who is 18, 19, or 20 years of age who has a chronic debilitating disease or condition of one or more physiological or organ systems which generally make the individual dependent upon 24-hour-per-day medical, nursing, or health supervision or intervention."

28. Petitioner cannot toilet independently and requires incontinence supplies.

29. Petitioner is unable to feed himself or eat solid food. He requires supplemental nutrition through a feeding pump and gastrostomy tube which requires consumable medical supplies like extension tubing and syringes.

30. On or about February 2021, Petitioner's guardian and biological mother requested that Petitioner's managed care plan, Children's Medical Services (CMS), assist Petitioner with enrollment on to the LTC Waiver.

31. CMS contracts with the Agency to administer Medicaid.

32. On or around that same time, Petitioner's CMS care coordinator, relying on the Agency's statement, instructed Petitioner's mother that the enrollment process could not begin because Petitioner was not 6 months away from turning 21. The CMS care coordinator further informed Petitioner's mother that Petitioner would not be eligible for priority enrollment on to

the LTC Waiver unless he was authorized for and actively receiving private duty nursing services.

33. In February 2022, Petitioner's mother was once again informed that Petitioner would need to be receiving skilled nursing services to bypass the LTC Waiver screening process and that, if she wanted to apply Petitioner for the LTC Waiver, she would have to contact ElderSource (which is Duval County's ADRC responsible for non-priority LTC Waiver screening and waitlist placement). *See Fla. Stat. 409.979(3)(a)(1)* ([p]ursuant to s. 430.2053, aging resource center personnel certified by the Department of Elderly Affairs shall perform the screening for each individual requesting enrollment for home and community-based services through the long-term care managed care program).

34. The grounds for CMS's denial were based on the Agency's statement which acts as an unadopted rule; CMS found that Petitioner was not eligible for priority enrollment pursuant to Fla. Stat. §409.979(3)(f)(1) because he was not yet 6 months away from turning 21 and because he was not authorized for and receiving private duty nursing services.

35. Based on the Agency's statement, because Petitioner is not 6 months away from turning 21, he is not yet eligible for priority enrollment on the LTC Waiver even though he meets the criteria set forth in Fla. Stat. §409.979(3)(f)(1). Dr. Nathawad's clinic staff have counseled Petitioner's mother that there have been many times when, because of the delay (being required to wait until 20 ½ to begin the LTC Waiver priority enrollment process), their patients, upon turning 21, lose access to critical services like incontinence supplies since the priority enrollment process is not finished within the 6-month period. Thus, Petitioner's mother is concerned that, if Petitioner is not able to enroll in the LTC Waiver until he turns 20 ½ years old, then the delay will cause a lapse in services because, when he turns age 21, his current Medicaid plan will no

longer cover certain services, like consumable medical supplies, that he requires to live safely and healthily in the community.

36. Additionally, as stated above, based on the Agency's statement, because Petitioner does not actively receive private duty nursing services, he is not eligible for priority enrollment on the LTC Waiver even though he meets the criteria set forth in Fla. Stat. §409.979(3)(f)(1). While Petitioner is not authorized for and does not receive private duty nursing services, Dr. Nathawad is of the opinion that private duty nursing services are medically necessary for Petitioner and has offered to coordinate those services on his behalf. Dr. Nathawad's clinic staff have also told Petitioner's mother that patients have been denied priority enrollment on the LTC Waiver because they were not actively receiving private duty nursing.

37. Petitioner's mother, however, chooses to provide Petitioner all his hands on care and, therefore, does not utilize private duty nursing. She will continue to make this choice for as long as she is able. Importantly though, in the future, if something were to happen to Petitioner's mother and she could no longer care for him, Petitioner would require private duty nursing services to continue living in the community.

38. CMS, by relying on the Agency's statement and denying Petitioner priority LTC Waiver enrollment, substantially affects his right to bypass the waitlist and screening process pursuant to Fla. Stat. §409.979(3)(f)(1) as an 18, 19, or 20 year old individual "who has a chronic debilitating disease or condition of one or more physiological or organ systems which generally make the individual dependent upon 24-hour-per-day medical, nursing, or health supervision or intervention." This, in turn, jeopardizes his ability to live safely and healthily in the community because, without LTC Waiver enrollment by age 21, he will lose Medicaid coverage of critically needed services.

B. Petitioner Disability Rights Florida

39. Any association or organization who demonstrates that many of its members stand to be or are affected by an unadopted rule can request that an Administrative Law Judge determine that the rule is an invalid exercise of delegated legislative authority pursuant to Fla. Stat. §§ 120.56(1) & (4). Petitioner, Disability Rights Florida, meets these criteria and has standing to bring this proceeding.

40. Disability Rights Florida is a private, not-for-profit organization that is the Florida's designated protection and advocacy (P&A) system. P&A systems are located in each state and U.S. territory and their purpose is to advocate for the protection of personal and civil rights of individuals with disabilities, including individuals with developmental disabilities.

41. Disability Rights Florida is designated by the state of Florida as Florida's P&A organization which includes the responsibility to carry out the mandates of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the "Act"). *See* 45 C.F.R. §1326.20.

42. Pursuant to the Act and Florida's designation, Disability Rights Florida is authorized to "pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements." 42 U.S.C. §15043(a)(2)(A)(i).

43. Furthermore, under federal law, Disability Rights Florida is required to establish an Annual Statement of Goals and Priorities which must be developed through formal public input. *See* 42 C.F.R. §§1326.22(c) & (d). As part of its current, 2018-2021 Strategic Long-Range Plan, Disability Rights Florida seeks to: "eliminate barriers to inclusion by increasing access to opportunities and independence for persons with disabilities." This includes the 2022

organizational objective that “individuals with disabilities shall have access to long-term care programs that encourage individual choice and community-based service delivery.”

44. Disability Rights Florida has a uniquely relevant interest in the subject matter of this action as the system statutorily enabled to pursue remedies on behalf of individuals with developmental disabilities. *Id.*

45. Disability Rights Florida has standing to assert claims on behalf of its constituents via participation in this lawsuit, as many of its constituents are made up of Medicaid-eligible young adults with complex medical conditions in need of enrollment on to the LTC Medicaid Waiver.⁵ In turn, all Medicaid eligible young adults with complex medical conditions in need of LTC Medicaid Waiver enrollment are constituents of Disability Rights Florida, an organization designated by federal and state law to advocate for these constituents, including advocacy related to their access to the LTC Medicaid Waiver.

46. The constituents of Disability Rights Florida, medically complex young adults in need of treatment, services, and habilitation offered by the LTC Medicaid Waiver, are substantially affected due to the Agency’s statement that narrows the criteria for their priority enrollment on to that Waiver. Thus, the interest Disability Rights Florida seeks to protect as a Petitioner in this matter is germane to the organization’s purpose.

47. Specific examples of Disability Rights Florida’s advocacy on behalf of this group of constituents includes:

⁵ Under the Act, the term “developmental disability” means a severe, chronic disability of an individual that— (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. 42 U.S.C. §15002(8). Medically complex young adults described at Fla. Stat. 409.979(3)(f)(1) fall under this definition of “developmental disability.”

- a. *Trautenberg v. Levine*, Case No. 1:06-CV-20695-Altonaga/Turnoff (S.D. Fla., March 20, 2006) (represented a 21-year-old medically complex young adult who lost access to Medicaid services necessary for him to live safely and healthily in the community because the state failed to transition him into an HCBS Medicaid Waiver).
- b. *U.S. v. Fla.*, Case No. 0:13-CV-61576-WJZ (S.D. Fla., July 22, 2013) (sought to intervene as an organizational party to represent the rights of medically complex young adults who were denied Medicaid services necessary to live safely and healthily in the community and instead were institutionalized in skilled nursing facilities).
- c. Direct representation of individual client, K.M., against the Palm Beach County School District when K.M. lost critical Medicaid home health services necessary to remain integrated into the community and at school because K.M. turned 21 and the state failed to transition him into an HCBS Medicaid Waiver.

VI. Request for Relief

48. Petitioner respectfully requests that an order be entered:
- (A) Finding and declaring that the Agency statement meets the definition of a rule set forth at Fla. Stat. §120.52(16);
 - (B) Pursuant to Fla. Stat. §§ 120.56(1)(a) and 120.56(4), finding and declaring that the Agency’s statement is an invalid exercise of delegated legislative authority as defined in Fla. Stat. §§ 120.52(8)(a), (c) & (e) because:
 - i. The Agency materially failed to follow the applicable rulemaking procedures or requirements in violation of Fla. Stat. §120.54(1)-(3) in relying on the statement as an unadopted rule,
 - ii. The Agency’s statement, which meet the definition of a rule, enlarges, modifies, or contravenes the specific provisions of law, Fla. Stat. §409.979(3)(f)(1) it seeks to implement, and
 - iii. The Agency’s statement is arbitrary and capricious.
 - (C) Finding and declaring that the Agency’s determination of Petitioner’s substantial interests is based on that invalid exercise of delegated legislative authority;
 - (D) Awarding attorney’s fees and costs to pursuant to Fla. Stat. §120.595(4); and
 - (E) Awarding any other appropriate relief.

Respectfully submitted this 1st day of March 2022.

Petitioner by his Attorneys,

/s/ Katy DeBriere

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CERTIFICATE OF SERVICE

I hereby certify that a copy of the foregoing has been sent via electronic mail to the following on this 1st day of March 2022.

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