



**After FHJP and DRF petition, Agency for Health Care Administration takes comprehensive corrective action ensuring medically fragile Medicaid youth do not experience a break in coverage of critical medical services**

**FOR IMMEDIATE RELEASE**

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**TALLAHASSEE** — The Agency for Health Care Administration (the Agency) was forced to take comprehensive corrective action after improperly denying a 20-year-old Medicaid beneficiary's request to bypass the 55,000-person waitlist to be immediately enrolled into Florida's Long Term Care Waiver program pursuant to state law protections.

The Florida Health Justice Project (FHJP) and Disability Rights Florida (DRF) petitioned the Division of Administrative Hearings because the Agency improperly added an additional requirement in applying the statute that affords priority waiver enrollment to children aged 18, 19, or 20 with a chronic debilitating disease or condition in need of 24-hour health intervention or supervision. Under the Agency's challenged practice, the only individuals allowed to bypass the lengthy waitlist and afforded priority enrollment were those who used Medicaid's nursing services. FHJP's client, Caleb Jones, had been denied priority enrollment under the Agency's overly narrow interpretation because his primary caretaker and mother, Marcia Banks Jones, provides her son all of his hands-on care herself.

Under Florida's Medicaid program, if Jones was not enrolled in the waiver by age 21, he would have lost coverage of vital Medicaid services and supplies, which, as a person with quadriplegic cerebral palsy, he requires for his daily health and well-being. While children under age 21 receive these services under federal Medicaid law, the services are greatly reduced as soon the child turns 21, unless the child is already enrolled in a waiver.

Additionally, Disability Rights Florida had standing as a plaintiff in this case because of its role as the state's designated protection and advocacy system for persons with disabilities. As such, the organization was able to represent all individuals with disabilities in this case and influence systemic change.

Katy DeBriere, FHJP legal director, lauded the Agency's corrective actions in response to the petition. These actions include: amendments to Agency contracts with entities that assist in the administration of Florida's Medicaid program, the development and transmittal of a new form and instructions to

managed care plans to ensure all eligible young adults are properly referred for priority enrollment, and formal amendments to training manuals and policies relied on by other administrative agencies and managed care plans to determine who is eligible for priority enrollment.

“We appreciate the Agency recognizing its interpretation of this important state law protection was erroneous and resulted in otherwise eligible individuals being placed on a lengthy wait list and thus going without critical services for an interminable amount of time,” DeBriere said. “Families, like the Jones, shouldn’t be punished for choosing not to use all Medicaid services to which they are entitled.”

Alison DeBelder, director of the System Reforms Team at Disability Rights Florida, the state’s designated Protection & Advocacy (P&A) system, represented Jones as well as her organization, who regularly advocates and litigates on behalf of individuals with complex medical needs, said the decision will positively impact the clients they serve. ““The robust corrective action undertaken by the Agency should curtail future illegal denials of enrollment for medically fragile young adults, so they do not face the same stress as Mr. Jones and other Disability Rights Florida constituents,” DeBelder said.

Mr. Jones’ mother shared her gratitude for the Agency’s response, stating “I know firsthand what it takes to care for a young adult like my son, Caleb. That’s why it was important to me that we bring this case; so overstretched families like mine have one less thing to worry about in navigating care for their children. I appreciate that the Agency recognized this problem and agreed to remedy our concerns, not just for my family, but for all families in Florida.”

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

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