



January 8, 2024

Bureau of Medicaid Policy,
Agency for Health Care Administration,
2727 Mahan Drive, MS 20,
Tallahassee, Florida 32308.

Submitted via e-mail to: FLMedicaidWaivers@ahca.myflorida.com

Re: Comment on Developmental Disabilities Individual Budgeting (iBudget) Waiver Renewal Request

Disability Rights Florida appreciates the opportunity to comment on the Developmental Disabilities Individual Budgeting (iBudget) Waiver Renewal Request. Disability Rights Florida (“DRF”) was founded in 1977 as Florida’s statewide protection and advocacy system for individuals with disabilities. As Florida’s Protection and Advocacy (“P&A”) agency, DRF seeks to protect the rights of individuals with disabilities. DRF’s authority flows from the Developmental Disabilities and Bill of Rights Act of 2000 (DD Act), the Protection and Advocacy for Individuals with Mental Illness Act of 2000 (PAIMI Act), and the Protection and Advocacy for Individual Rights (PAIR) program established under the Rehabilitation Act of 1973. As Florida’s federally mandated P&A, DRF is granted broad authority to protect and advocate for the rights of persons with disabilities. See *Virginia Office for Prot. & Advocacy v. Stewart*, 563 U.S. 247 (2011). DRF provides legal representation and advocacy services statewide for individuals enrolled in the Medicaid program, including individuals enrolled in Florida Statewide Medicaid Managed Care Long-Term Care Waiver (“LTC Waiver”) and Florida Medicaid’s Developmental Disabilities Individual Budgeting Waiver (“iBudget Waiver”).

DRF commends AHCA for the proposed change revising the definition of Intellectual Disability revised from IQ 60-69 inclusive to IQ 60-70 inclusive, for those with a secondary impairment/limitation. This change will positively affect Floridians with disabilities who face barriers beyond those that may have not been apparent, and/or resulted from their primary diagnosis. Further, it is a needed step in the right direction, given the fact that research has



shown IQ measures to be particularly inaccurate when applied to the developmentally disabled population¹.

However, based on our history representing individuals with disabilities and experience with Florida Medicaid, including the iBudget Waiver, we have grave concerns regarding the proposed change in the waiver's name to the "Unique Abilities Individual Budgeting Waiver"

As it stands, the current name "Developmental Disabilities Individual Budgeting Waiver" adequately reflects the waiver's function, to serve what the state of Florida defines as its developmentally disabled population. Changing the name as proposed creates room for ambiguity in the state's provision and delivery of vital services upon which thousands of Floridians depend. Similarly, changing the term "waitlist" to "pre-enrollment" within the waiver to reflect language amended by the 2023 Florida Legislature does not erase the fact that Floridians with disabilities have gone without services to which they are entitled for decades. A waitlist by any other name is still a waitlist, and thousands of disabled Floridians are still not receiving services for which they have been deemed eligible.

As of November 2023, the state itself cites over 21,500 Floridians as not receiving the services they need; up to and including, 210 individuals whose needs have been identified as intensive.² Moreover, once on the waiver, adequate services are far from guaranteed. According to a report from the Florida Developmental Disabilities Council, as recently as 2017 (the last public report available), Florida was 50th out of 50 states plus the District of Columbia in total adjusted spending for publicly funded programs for persons with intellectual and developmental disabilities.³ As evidenced by these facts, the state's current developmental disabilities service provision systems have problems far beyond those able to be fixed by the renaming that is proposed here. Thus, to allow for such is to endorse the erasure of the needs of Florida's developmental disability community; needs which are simply human and far from unique.

It should be noted that the state's newfound interest in wordsmithing is not necessarily a recent phenomenon. For instance, in 2021 Senate Bill 524 changed the name of voting "drop boxes" to "secure ballot intake stations" in a move which may have resonated public opinion at the time, but beyond creating confusion and numerous access issues did not fundamentally change the function of those apparatuses. Similarly, given the magnitude of the crises frequently facing individuals who either are (or should be) served by the state's developmental disabilities waiver,

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4613563/>

² CP_House_HHHSC24_20231211_13 (1)

³ [State-of-the-State-Report.pdf \(fddc.org\)](#)



language cannot and should not be "spun" through marketing or public relations campaigns. Personal identity, lived experience, and the valuable perspectives of countless Floridians with disabilities cannot be legislated away. To do so risks deflecting from the importance of the stakes that are in balance for Florida's disability communities, stakes that Disability Rights Florida believes are existential at their core.

In our laws as well as in the broader public discourse, "Disabled," "disability," and related terms have been utilized for decades. Although not always universally defined or applied, these terms are universally familiar; and familiarity plays an important role in the ease and uniformity with which services are provided and accessed. Someone searching for needed services and support has a high chance of finding at least a few resources which they can use by conducting their search with the term "disability." The same cannot be said for euphemisms, which by nature of their use and application are necessarily open to interpretation. Rendering identity as well as the legal protections that align with identity, whether in casual conversation or through legislative prescription and enshrinement, leaves the door open for discrimination in a way that is not only unconscionable but must be understood as having unpredictable and potentially severe social and policy-related consequences.

This is evidenced, in part, by the fact that an individual utilizing the search term "unique abilities" in an online search leads not to resources such as those that the Agency for Persons with Disabilities or the Agency for Healthcare Administration provide, but rather to self-help resources.⁴ In fact, most of the disability-related resources which reference "unique abilities" come from Florida's own attempt to market disability as such. However, a marketing scheme is not what Floridians with disabilities deserve or want.

The essence of the Olmstead decision upon which the provision of Home and Community-Based Services is predicated asserts the right to autonomy of disabled individuals. And while no preference is universal, the disability community at large rejects these euphemisms--which many regard as extremely harmful--in favor of the word disabled and other self-chosen identifiers. For many, using the words disabled and disability, and even more colloquial terms such as *crip*, *mad*, or *cyborg* are a purposeful language choice designed to reclaim the power and strength behind an identity that many outside the community see as derogatory, but which people with disabilities themselves openly and authentically celebrate.

Recent movements such as #CripTheVote and #SaytheWord are two of the many disability-led initiatives that exemplify such a reclamation. Some individuals also prefer person-first language

⁴ <https://resources.strategiccoach.com/the-multiplier-mindset-blog/what-is-unique-ability>



("person with a disability"), while others will use both person and identity-first language interchangeably. Regardless of an individual's personal choice on how to identify, the reclamation movement emphasizes celebration of disabled autonomy. How a person and larger community define themselves should never be open to debate amongst those outside the community; nor should others' comfort level dictate the perpetuation and use of euphemisms in areas of public service or concern. To put it simply, identity cannot and should not be defined by governmental entities.

That members of the disability community prefer disability-affirming language is not a new phenomenon. In fact, it is a large part of the reason that laws such as the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) *contain* these specific terms. These laws expelled outdated and harmful language, such as the R word, and put disabled and disability in place to usher in a new era of disability rights and respect. The case for using the term 'disability' isn't and shouldn't be seen as merely a matter of preference. The words we use deserve careful consideration as they have the power to shape our laws and society. The disability community adopted the slogan "nothing about us without us" to remind others that people with disabilities should be included in policy discussions about them. In this instance, meaningful input should have been collected regarding how language changes such as "disabilities" to "unique abilities" or "waitlist" to "pre-enrollment list" make affected people feel and impact the discourse around the very real barriers they face. Something that we as the P&A are deeply concerned the state has not done here.

Respectfully submitted,

Disability Rights Florida