

Policy Brief

End the Wait! *for Floridians with Developmental Disabilities*

What is the problem?

There are now 22,718 Floridians with developmental disabilities (DD) on a waitlist to receive services from Florida's iBudget Developmental Disabilities Medicaid Waiver. The Florida's iBudget provides home and community-based services that support daily activities of living, personal, medical, and dental care. Many have been waiting in excess of five years. Additional funding is urgently needed to reduce the iBudget Waiver Waitlist.

Why is this issue important?

Without services people with DD and their families can endure major financial, physical, and emotional burdens with lasting social and economic consequences for the state. Individuals with DD need services to enhance their quality of life as well as that of their family caregivers in order to achieve a fulfilling life.

Who does this impact?

The vast majority of people with DD live with their family. Without iBudget support, caring for individuals with DD can be very expensive and time consuming. Caregivers may have less time available to be employed when they are providing such assistance, and reducing their ability to save for future financial needs. Studies have found that two-thirds of Florida's caregivers earn less than \$15,000 a year¹, yet the estimated direct cost for caring for their loved one with DD is \$8000 per year, a figure which rises to over \$25,000 when including potential loss from their reduced earnings/labor force participation and reduced future income.²

What is the iBudget Waiver?

The iBudget Waiver is how Florida pays for community-based services for people with DD.

How does Florida compare to other states?

Of 50 U.S. states, **Florida ranks 49th** in spending for intellectual and developmental disability services.³ Florida's fiscal effort for DD services has decreased 10% since 2007.³

Why should we transition people with DD off the Waiver Waitlist?

- Individuals with DD who request services often want more independent, productive lives, so they can also contribute to the community.
- Serving more people with DD means assisting more families who informally provide care. This will help reduce financial, physical, and emotional strains on caregivers, many of whom are aging.
- Transitioning individuals off the iBudget Waiver Waitlist helps maintain the provider infrastructure and quality, and encourages new providers to work in the field of developmental disabilities.



Florida’s Waitlist Priority Groups

Currently, there are seven categories in the DD Waitlist to prioritize those with greater needs (see Table 1 for brief descriptions). Unfortunately, those in lower categories of assessed need are less likely to be served, and thus languish for unacceptably long periods on the waitlist. Only a substantive change in assessed need (in either the individual, or their family caregiver’s circumstances) will result in movement to a higher category and eventual receipt of services.

Table 1. Individuals on DD Waitlist by Priority Group

Cat	Description	Total	%
1	Crisis	0	0.0%
2	Children in Welfare System	0	0.0%
3	Intensive Needs	848	3.7%
4	Caregiver Over Age 70	218	1.0%
5	Transition from School	24	0.1%
6	Age 21 and Over	12,057	53.1%
7	Age Under 21	9,548	42.0%
	Priority Not Yet Assessed	23	0.1%
Grand Total		22,718	100%

Source: Agency for Persons with Disabilities as of January 4, 2021

Floridians of all ages are being adversely affected by the waitlist. A looming crisis is Florida’s rapidly aging population. Of those people who are living with their family caregivers, 33% are living with their aging caregivers aged 60+, the highest percentage in the nation when compared with other states.³ At present, there are still Floridian caregivers who have to wait until they reach the age of 70, before their adult child is prioritized for iBudget waiver services. Alignment with current standard retirement age of 65

References

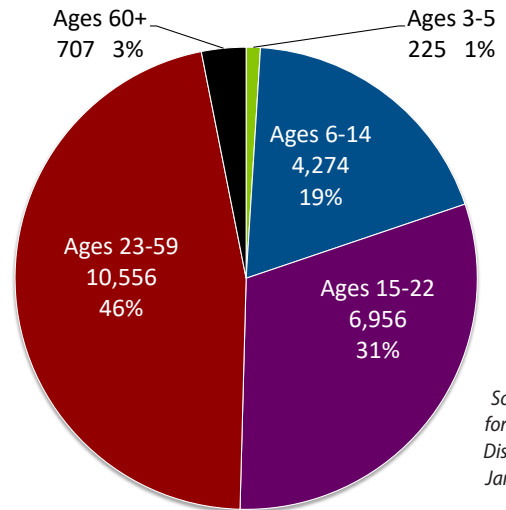
- Andresen, E., Hall, A., DeFries E., & Ali, A. (2008). *Agency for Persons with Disabilities (APD) waiver program wait list survey*. Retrieved from Florida Office on Disability and Health, https://fodh.phhp.ufl.edu/files/2011/05/APD-Final-Report_08.08.08_Revised.pdf
- Stabile, M., & Allin, S. (2012). The economic costs of childhood disability. *The Future of Children*, 22, 65-96.
- Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Wu, J., & Haffer, L. (2017). *The State of the States in Intellectual and Developmental Disabilities: 2017*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Diament, M. (2016, August 30). Waiting list placements may violate ADA. *Disability Scoop*. Retrieved from <https://www.disabilityscoop.com/2016/08/30/waiting-list-may-violate-ada/22685/>

Suggested Citation

Perkins, E. A., Kose, L., & Hooper, M. (2021). *End the Wait! Developmental Disability Policy Brief*. Florida Center for Inclusive Communities/Florida Developmental Disabilities Council.

years would recognize and appreciate the lifelong caregiving duties already undertaken and allow these caregivers the opportunity to prioritize their own health and aging needs.

Figure 1. Individuals on the Waitlist by Age Group



Source: Agency for Persons with Disabilities as of January 4, 2021

Conclusion

Under the Americans with Disabilities Act (ADA), individuals with DD may be entitled to receive home and community-based services in the least restrictive environment and most integrated settings. Keeping these individuals on the waitlist for years may not only violate their right to access these services⁴ but also hinder their capacity, growth, and motivation to pursue a fulfilling life. Increased funding to substantively reduce the iBudget Waitlist will result in Floridians with DD and their families having appropriate supports to prosper and fully enjoy inclusive community life.

Recommendations

- A sustained financial commitment to effectively reduce the waitlist by 10% each year and to address this ongoing backlog.
- Reduce the age requirement of category 4 caregivers from 70 to 65.
- Fund categories 3 (intensive needs) and 4 as a matter of urgency.

For more information, contact Dr. Liz Perkins at eperkins@usf.edu or visit www.ddwaitlistfl.org.

