FAQs

Florida’s Developmental Disabilities Home and Community-Based Services (DD-HCBS) Medicaid Waiver & Waitlist

1. What are developmental disabilities?

Developmental disabilities include a diverse set of conditions that are recognized at birth or during childhood and alter the usual course of development. Florida’s Developmental Disabilities Medicaid Waiver (commonly referred to as the Individual Budgeting Waiver or iBudget Florida) provides services to individuals with any of six conditions: Down syndrome, intellectual disability, spina bifida, autism, cerebral palsy, and Prader-Willi syndrome.

These conditions have a wide array of physical and mental symptoms, which often make it difficult for individuals to obtain employment, live independently, or complete activities of daily living (ADLs) such as eating, bathing, and toileting, without assistance.

2. What is the Developmental Disabilities Medicaid HCBS Waiver program?

Home and Community-Based Services (HCBS) Waiver programs are Medicaid programs authorized by Title XIX of the Social Security Act, Section 1915(c) that provide services in the home or local community for individuals who would otherwise require institutional care in a hospital, nursing facility, or intermediate care facility. These programs serve a variety of targeted populations.

The Developmental Disabilities HCBS Waiver is administered by the Agency for Persons with Disabilities (APD). It covers services for individuals with developmental disabilities, including personal care assistance, supported employment, and adult day care.

Through various programs (but primarily the DD-HCBS Medicaid Waiver), APD is mandated to provide “community-based services [to] enable individuals with developmental disabilities to achieve their greatest potential for independent and productive living, enable them to live in their own homes or in residences located in their own communities, and permit them to be diverted or removed from unnecessary institutional placements.” (s. 393.062, F.S.)
3. What are the benefits of increased funding for DD-HCBS Waiver services?

**Cost Savings to the State**

The average cost of institutional care in Florida is $147,460 per year, compared to $29,215 for home and community-based Medicaid Waiver services.¹

**Increased Employment & Productivity**

- Most adults with developmental disabilities want to be employed and to support themselves financially.²
- Research shows that training and development services yield:³
  - More job placements
  - Higher wages
  - More work hours per week.
- Waiver services also allow caregivers to return to the workforce by reducing caregiving burdens.

**Improved Quality of Life & Inclusion**

- Waiver services help individuals with developmental disabilities participate fully in their communities through work as well as educational, recreational and social activities.
- Waiver services reduce stress on caregivers, leading to improved health.
- Waiver services meet basic needs such as bathing and toileting that caregivers may have only limited capacity to provide.

---

³ See previous footnote.
4. **How much funding is needed enroll Waitlist members on the Waiver so they can begin receiving services?**

APD has requested $20 million in new funding for FY 14-15, enough to enroll more than 1,200 individuals from Waitlist Categories 3 and 4 (the most critical categories) on the Waiver program. Several developmental disabilities stakeholders in Florida have joined in proposing a long-term plan that would enroll an additional 1,500 people per year on the Waiver program beginning in FY-15-16. This plan would require new funding of $20-$28 million per year, according to a cost estimate by the Florida Developmental Disabilities Council using data provided by APD.

5. **Why is there a waiting list for the Developmental Disabilities HCBS Waiver?**

APD’s budget is not sufficient to serve everyone who is eligible for services under the DD-HCBS Waiver. Therefore, more than 20,000 people with developmental disabilities are currently on a waiting list for the Waiver. Services are typically only offered when a family reaches a crisis such that the individual faces the threat of immediate institutionalization. Florida has experienced steady population growth in recent decades; with this growth, comes an increasing number of Floridians with developmental disabilities. Meanwhile, the Waiver program has experienced major funding cuts in recent years. The $20 million in new funding requested by APD for FY 14-15 would only return the Waiver to its FY 08-09 level.

6. **What services do people on the Waitlist need?**

Families of individuals on the Waitlist often need help to care for their family member with activities of daily living (ADLs) such as eating, bathing, and toileting. Caregivers often become overwhelmed with these tasks, especially as caregivers themselves become elderly or fall ill.

Individuals with developmental disabilities often need meaningful activities to do during the day such as adult day training services. They may need transportation and supported employment services, so that they can join the workforce and participate fully in their communities. These individuals often also need basic medical and dental services that are not available unless they are enrolled on the Waiver.
About 45% of Waitlist members have significant behavioral problems. This includes self-harm behaviors, aggression toward others, destruction of property and running away. Behavior analysis services help the individual improve their behavior and learn to interact appropriately with others.

7. **Apart from seeking new funding from the Legislature, what is being done to address the needs of those on the Waitlist?**

The Agency for Persons with Disabilities has developed an online resource directory that helps individuals with developmental disabilities and their families find services and supports in their communities. APD has also established a community affairs unit for each region to focus on community partnerships to expand resources available to Waitlist members.

The Waitlist Strategic Plan Implementation Task Force, representing people with developmental disabilities, their families, and other key stakeholders, is working to implement several innovative strategies to address the ability of Waitlist members to be productive and participate in their communities. Some of these strategies focus on fostering community-based services provided by volunteers, charitable organizations, and mutual assistance groups. Others focus on promoting awareness of existing services and linking those in need to them. Nevertheless, many critical needs of Waitlist members cannot be met without new funding for Waiver services.

8. **How has the $36 million in new funding appropriated for FY 13-14 affected the Waitlist?**

Because of the $36 million allocated by the Legislature in FY 13-14, Waiver services have been or will be provided to 1,600 individuals who were on the Waitlist. This was a major step in the right direction; however, more than 20,000 people with developmental disabilities are still waiting for services.

---

4 Florida Developmental Disabilities Council (2013). *Home and Community Based Services Waiver Waitlist Strategic Plan*. 
9. **How does the lack of Waiver services impact families?**

Nearly all (92%) of individuals enrolled on the Waiver live with their families. Without Waiver services, families experience significant financial, physical and emotional strain with lasting social and economic consequences for them and their communities.\(^5\)

- Having a child with disabilities makes it more likely that a parent will reduce their work hours or leave the workforce entirely.\(^6\)

- In many families, caring for an individual with developmental disabilities consumes more than half of every dollar earned:
  - Two thirds of caregivers report an annual household income of less than $15,000.\(^7\)
  - Out-of-pocket costs to care for a child with developmental disabilities have been estimated at $8,000 annually.\(^8\)

- Care giving stress can be deadly. Elderly caregivers without adequate support are 63% more likely to die within a four-year period compared to non-caregivers.\(^9\)

---

\(^5\) Florida Developmental Disabilities Council (2013). *Home and Community Based Services Waiver Waitlist Strategic Plan.*


\(^7\) Florida Developmental Disabilities Council (2013). *Home and Community Based Services Waiver Waitlist Strategic Plan.*
