



Florida Developmental Disabilities Council, Inc.

Five-Year State Plan 2027-2031





The Florida Developmental Disabilities Council, Inc. (FDDC) operates under the federal Developmental Disabilities and Bill of Rights Act of 2000. Funding is provided through the Administration for Community Living, whose fundamental principle is that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the opportunity to participate fully in their communities. The FDDC is a member of a national network of state councils that has existed for more than 50 years.

The main purpose of FDDC's 26-member Governor-appointed advisory board is to leverage federally appropriated dollars to facilitate major systems change, affect policy, build capacity within existing and future delivery systems, and to advocate with,

and on behalf of, individuals with intellectual and developmental disabilities (I/DD).

In Florida, the FDDC is the only funded, independent entity with the authority to facilitate collaborative partnerships among all state agencies, universities, and disability organizations and the designated authority to advocate with the Executive branch and Legislature.

The FDDC's priorities emerged from national and statewide data and stakeholder input in the format of focus groups, key informant interviews, and surveys from persons with intellectual and developmental disabilities, their families, and the people who support them.





Priority Area #1: Access to Services

Increase Access to Quality Services and Resources for Individuals with Intellectual and Developmental Disabilities and Their Families

Presently, no single, easy-to-use point of access exists that connects individuals with I/DD and their families to various needed services and programs. Current information and resource platforms are fragmented and difficult to navigate, creating barriers to timely access.

The FDDC has been working to improve the way persons with I/DD and their families can easily find, access, and use services across Florida. It will be advancing the Access to Services through Knowledge (ASK) information and resource delivery system as a central, web-based platform devoted to local, community resource needs that have been identified through extensive research.

The FDDC recognizes that access to services depends on the availability and quality of supports. Efforts will be made to improve availability of qualified providers and increase usage of evidence-based tools that will support quality services and outcomes across home and community settings.

What We Learned from Our Communities

- There was common agreement among self-advocates that some of the biggest access issues they face are:
- Clear navigation to find the right services through the right agency or provider
 - Lack of knowledge of services and how to access them

Self-Advocate and Caregiver/Family Member Surveys:

Over 40% of self-advocates said “no, I did not receive all services needed in the past two years”

About 16% of self-advocates did not know what services they could get at all

Over 25% of Caregivers/Family Members listed “How to get services” as a top information need

“System fragmentation – there is profound client overlap but not profound coordination of clients among state agencies and service organizations.” – Key Informant Interview

“You have to fight 24 hours a day to get anywhere with issues” and “It’s exhausting trying to navigate the system.” – Self Advocate and Caregiver/Family Member Focus Groups

As of 2022, it was estimated that there are 351,468 persons with I/DD living in Florida based on a general prevalence rate of 1.58%.¹ Comparative prevalence rates estimate 439,049 individuals currently live with intellectual and developmental disabilities in Florida – 299,900 children 0-17 years² and 139,149 adults 18 and older.¹ From 2019-2021, national data reflected an increase in the prevalence of diagnosed developmental disabilities among children aged 3-17 years from 7.4% to 8.56%.³ Documented prevalence of I/DD in Florida is a conservative estimate that likely underestimates the true I/DD population size.

References

1. Larson, S. L. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106(3), 231-252.

2. Zablotsky B, Black LI, Blumberg SJ. Estimated Prevalence of Children With Diagnosed Developmental Disabilities in the United States, 2014-2016. NCHS Data Brief. 2017;(291):1-8.

3. Zablotsky B, Ng AE, Black LI, Blumberg SJ. Diagnosed Developmental Disabilities in Children Aged 3-17 Years: United States, 2019-2021. NCHS Data Brief. 2023;(473):1-8.

Priority Area: ACCESS TO SERVICES

Goal 1: Individuals with intellectual and developmental disabilities (I/DD) and their families will have increased knowledge of, and expanded access to, comprehensive and high-quality community resources, services, and supports across the lifespan.

Objective 1.1: By September 30, 2031, an Access to Services through Knowledge (ASK) web-based information and resource system will be established, utilized by family members statewide, and result in increased access for individuals with I/DD and their families to services and supports aligned with their diverse needs across the lifespan.

Key Activity 1.1.1: Identify and update or develop an interactive Access to Services through Knowledge (ASK) web-based platform of key community resources and tools for families through state-of-the-art technology in a user-friendly and accessible format.

Key Activity 1.1.2: Plan and conduct online or onsite statewide utilization training for family members, waiver support coordinators, case managers, service providers, and others deemed appropriate on the new online Access to Services through Knowledge (ASK) system.

Key Activity 1.1.3: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve access to services for individuals with I/DD and their families.

Objective 1.2: By September 30, 2031, individuals with I/DD will have increased access to trained and qualified service providers who are adequately compensated across Florida, especially in rural and underserved communities, resulting in quality services across home and community settings.

Key Activity 1.2.1: Develop and implement a direct support provider training program in high schools, Florida’s technical colleges, state colleges, and/or other appropriate settings that includes strategies for targeted recruitment, certifications/credentialing, retention, and any other important factors previously identified.

Key Activity 1.2.2: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve the availability of qualified service providers and their delivery of quality services and supports across home and community settings.

Objective 1.3: By September 30, 2031, the provision of quality services for individuals with I/DD will be improved through increased access, availability, and use of evidence-based tools for assessing quality assurance that result in quality services and the level of care required to maintain a safe quality of life in the communities, environments, and settings where they are served.

Key Activity 1.3.1: Develop and implement capacity building activities designed to increase statewide use of the Best Practices in Case Management tools (i.e., “Working with Case Managers” Toolkit) by individuals with I/DD, families, case managers, supervisors, and program managers.

Key Activity 1.3.2: Develop and implement capacity building activities designed to increase statewide use of the Measuring Service Quality tools (e.g., residential, “Finding the Right Residential Provider,” supported employment; and adult day training).

Key Activity 1.3.3: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve the delivery of quality services and supports across home and community settings.

Priority Area #2:

Behavioral Health and Challenging Behaviors

Preserving Community, Preventing Crisis

For individuals with I/DD, unmet emotional and behavioral support needs can quickly disrupt family life, education, employment, and community participation. When appropriate support is unavailable or inconsistent, these individuals may experience preventable crises that impact their lives and threaten their ability to remain in home and community settings.

Access to trained professionals who understand the intersection of I/DD and behavioral health is necessary to maintain safe and stable lives for such persons. Without informed and coordinated responses, individuals with complex needs may face unnecessary interventions or placement in restrictive environments.

The FDDC will work to improve community-based behavioral health support across Florida by increasing access to qualified professionals, promoting effective practices, and establishing system responses that prioritize prevention and community integration.

What We Learned from Our Communities

Community support services (respite care, companion services, day services, getting and using assistive technology, counseling services, personal care assistance, faith-based services, and help with expenses) are recognized as essential to prevent displacement:

- In the past 12 months, 46.3% of self-advocates reported unmet community support service needs.
- In the next 12 months, 65.7% of self-advocates and 69.8% of caregivers/family members expect community support services to be a top service need.

Medical, mental health, dental, and wellness support services were among the top services used and needed in the future for persons with I/DD:

- These services were used the most in the past two years by both self-advocates (66.7%) and their caregivers/family members (69.2%).
- 61.6% of self-advocates think they will need these services in the next 12 months, and 69.8% of caregivers/family members thought these services will be needed for their persons with I/DD in the next 12 months.

There is a *“lack of knowledge and practice in our staff and behavior modification or how to handle those behaviors. It is widely known that people on the lower functioning – they are being neglected”* – Caregiver/Family Member Focus Group



About 27% of self-advocate survey respondents reported having both an intellectual or developmental disability and a diagnosed mental health condition. Among caregivers surveyed, 15.4% reported that their loved one had a co-occurring mental health diagnosis. Children with mental health, I/DD, and medical complexities were identified as especially underserved, particularly when they cannot be safely cared for at home.

Priority Area: BEHAVIORAL HEALTH AND CHALLENGING BEHAVIORS

Goal 2: Individuals with I/DD and co-occurring behavioral health needs, including challenging behaviors, and their families will have increased availability of services and supports to manage their behaviors and allow them to maintain a safe quality of life in family homes and community settings.

Objective 2.1: By September 30, 2031, individuals with I/DD and co-occurring behavioral health needs, including challenging behaviors, will have increased geographic access to, and availability of, trained behavioral health professionals and behavioral services across the lifespan that allow them to remain in their family homes, schools, and communities.

Key Activity 2.1.1: Implement, expand, and evaluate competency-based training curriculum and internships for Board Certified Behavior Analysts (BCBAs) and supervisory behavior therapists statewide to identify and address unmet needs and ensure quality services through improved access to trained behavioral therapists in all Florida counties.

Key Activity 2.1.2: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that increase statewide access to trained behavioral health professionals and quality behavioral services.

Objective 2.2: By September 30, 2031, increased use of effective practices for individuals with I/DD and co-occurring behavioral health needs, including challenging behaviors, will decrease unnecessary interventions and the number of these individuals placed in restrictive settings (i.e., hospitals, institutions, and inpatient programs).

Key Activity 2.2.1: Develop and implement capacity building and assessment activities designed to increase statewide use of the Council’s Dual Diagnosis Training and related resources by family members, agency employees, school personnel, social workers, and direct support providers and evaluate their impact on individuals with I/DD and co-occurring behavioral health needs, including challenging behaviors.

Key Activity 2.2.2: Develop and implement capacity building and assessment activities designed to increase statewide use of the Council’s First Responders Training and related resources by first responders, medical personnel, and mobile crisis units and evaluate their impact on individuals with I/DD and co-occurring behavioral health needs, including challenging behaviors.

Key Activity 2.2.3: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that decrease unnecessary interventions and the number of individuals with I/DD and co-occurring behavioral health needs, including challenging behaviors, being placed in restrictive settings.

Priority Area #3: Aging Families

Preparing for What Comes Next

A growing number of persons with I/DD and their caregivers in Florida are aging. As their needs change over time, families are often faced with uncertainty associated with long-term planning, housing, caregiving roles, and access to the appropriate support and services they need.

Aging individuals with I/DD and their caregivers must plan for the future while trying to navigate complex systems and limited resources. Without access to pertinent information, planning tools, and technological support options, families may experience increased stress and reduced ability to maintain stable and meaningful lives in their communities.

The FDDC will work to support the improvement of access to future planning resources and to advance the use of innovative, enabling technologies through case-based learning. This will inform decision-making and support aging caregivers and individuals with I/DD to remain connected and supported.

What We Learned from Our Communities

Critical issues facing aging caregivers from the Caregiver/Family Member Survey:

- **Worry about the future (54.2%)**
- **Fatigue, stress, and/or burnout (49.0%)**
- **Concern about financial issues (31.0%)**

One of the top information needs for caregivers and family members is finding support for an aging caregiver (21.7%).

“The creation of a dedicated system to support aging caregivers, addressing their long-term planning needs, reducing their daily stress, and providing peace of mind is important and is urgently needed.”
– Aging Caregiver Focus Group

Focus groups articulated numerous concerns for aging persons with I/DD as well as the family members who care for them. These included:

- **Continuity of care and services for the person with I/DD as the caregiver/family member faces their own physical health challenges**
- **Availability of ongoing program funding**
- **Service quality**

“The trajectory for family savings is severely changed when you have a child with a disability. [You] have less money to take care of yourself and child. When we are gone, who will make sure he gets the services he should be getting?” – Caregiver/Family Member Focus Group



A third of individuals with I/DD who live with family caregivers are living with aging caregivers 60 years and older, which is the highest percentage of any other state.¹ In our 2024 caregiver/family member survey, more than a third of caregivers were aged 65 years and older (35.6%), with more than one in five aged 70 years or older (21.5%).

1. Perkins, E. K. (2019). End the Wait! Developmental Disability Policy Brief. Retrieved June 11, 2025, from University of South Florida Center for Inclusive Communities

Priority Area: AGING FAMILIES

Goal 3: Aging individuals with I/DD and their families will have increased availability of services and supports needed by an aging population that allows them to maintain quality lives in their communities.

Objective 3.1: By September 30, 2031, aging individuals with I/DD and their family members will have increased access to future planning resources and tools designed to improve attainment and delivery of services and supports that meet the needs of an aging population.

Key Activity 3.1.1: Identify and/or develop person-centered future planning tools for families to minimally address long-term care planning in the domains of housing; legal; identification of primary caregiver(s); financial, including insurance options; day-to-day care, including daily activities and social connections, as well as employment; medical management, including medication; transportation; and technology solutions.

Key Activity 3.1.2: Plan, conduct, and evaluate an educational retreat or conference for aging families with one strand for parents and one strand for siblings to provide information on future planning and toolkits.

Key Activity 3.1.3: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address access and delivery of services and supports that meet the needs of aging individuals with I/DD and their families.

Objective 3.2: By September 30, 2031, recognizing the need for human interaction, aging individuals with I/DD and their families will also have increased knowledge of innovative, enabling technology options and models for addressing housing, social, and health needs that support them to live safely and independently in their communities.

Key Activity 3.2.1: Conduct an environmental scan and make recommendations for using innovative, enabling technology strategies (e.g., remote support, smart devices, mobile applications, communication systems, home sensors) to address the housing and support needs of aging individuals with I/DD and their families/caregivers in Florida.

Key Activity 3.2.2: Plan and conduct statewide training for families/caregivers on innovative, enabling technology strategies to address the housing needs of aging individuals with I/DD and their families in Florida.

Key Activity 3.2.3: Develop and coordinate all facets of implementation and evaluation grounded in IRB-approved research for a minimum of three case study demonstration homes using assistive technology experts and innovative, enabling technology strategies that support aging individuals with I/DD and their families/caregivers to maintain life in their homes through technology.

Key Activity 3.2.4: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address housing options that meet the needs of aging individuals with I/DD and their families.



Priority Area #4: Self-Advocacy Leadership

In the past 2 years, 46.3% of self-advocates reported unmet needs for community support services; 36.6% had unmet housing needs; 31.7% had unmet needs for medical, mental health, dental, or wellness supports; and 31.7% had unmet needs for therapies.

Elevating Those with Intellectual and Developmental Disabilities

Advocacy remains a critical driver of systems change and helps ensure decision makers understand the needs and issues of those living with I/DD (i.e. self-advocates) and their families. Developing knowledgeable and effective leaders among individuals with I/DD and family members to influence policymaking, public and private board and community involvement, and to educate and lead others remains imperative to the I/DD movement and an essential focus of the FDDC and our federal partners.

The FDDC will continue to focus on leadership development opportunities that increase participation in self-advocacy training and cross-disability leadership that allows individuals with I/DD to have a voice in shaping policy through the Partners in Policymaking national curriculum.

About Partners in Policymaking

Partners in Policymaking® (PIP) is a leadership training program that prepares adults with I/DD, parents, and caregivers of children and adults with I/DD to be effective advocates at the local, state, and federal levels. PIP teaches leadership skills and techniques to develop positive partnerships with elected officials, school personnel and other individuals who make policy decisions about services that you and/or your family use.

www.fddc.org/partners-in-policymaking

What We Learned from Our Communities

“Advocacy must go beyond simply securing access to services; it must also support individuals as they attempt to navigate complex systems, such as Medicaid.” – Self-Advocate and Caregiver/Family Member Focus Group

“Individuals with disabilities and their caregivers are not being taught how to advocate for themselves, further compounding the challenges they face.” – Focus Group Participant

“If you are in a position that you can’t advocate, then you just don’t get the services you need. You have to be able to read and write and keep good records. There is no advocacy to help them.” – Caregiver/Family Member Focus Group

“Part of PIP is learning the laws and learning to advocate for yourself. Half the battle is educating and for others to be understanding. Part of what I want to figure out is how to be that voice...sharing” – Caregiver/Family Member Focus Group

Self-advocate and caregiver/family member focus group participants felt that *“the presence of a dedicated advocacy program, one that could guide individuals and caregivers through the system, assist with overcoming barriers, and offer support when dealing with providers, would be most beneficial.”*

Priority Area: SELF-ADVOCACY LEADERSHIP

Goal 4: The number of individuals with I/DD trained as leaders, providing leadership training for other individuals with I/DD, and engaged in cross-disability leadership roles and coalitions will be increased.

Objective 4.1: By September 30, 2031, the state self-advocacy organization will increase the number of leaders trained, providing leadership training, and engaged in cross-disability leadership roles and coalitions.

Key Activity 4.1.1: Provide support (e.g., resources, training) for up to 20 state self-advocacy organization leaders to build their capacity to deliver leadership training to other self-advocates.

Key Activity 4.1.2: Provide support for trained state self-advocacy organization leaders to deliver information and training to other self-advocates.

Key Activity 4.1.3: Provide support for increasing or expanding opportunities for participation of individuals with I/DD in cross-disability and leadership coalitions.

Key Activity 4.1.4: Develop an annual, end-of-year state self-advocacy organization report.

Key Activity 4.1.5: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders that support the state self-advocacy organization.

Objective 4.2: By September 30, 2031, a minimum of 100 new Partners in Policymaking leaders among individuals with I/DD and family members of individuals with I/DD will increase their knowledge and provide evidence of their impact within public advocacy and cross disability leadership coalitions.

Key Activity 4.2.1: Utilize Partners in Policymaking to educate individuals with intellectual and developmental disabilities (I/DD) and family members of individuals with I/DD on self-determination, disability systems, and public policy.

Key Activity 4.2.2: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders that support Partners in Policymaking participants.

Objective 4.3: By September 30, 2031, a minimum of 100 dedicated Partners in Policymaking Alumni among individuals with I/DD and family members of individuals with I/DD will increase their knowledge and provide evidence of their impact within public advocacy and cross disability leadership coalitions.

Key Activity 4.3.1: Conduct needs assessment, follow-up educational activities (e.g., webinars, technical assistance), and evaluation with Partners in Policymaking Alumni to increase knowledge in areas of need, support advocacy actions, and assess post-program participation outcomes.

Key Activity 4.3.2: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders that support Partners in Policymaking Alumni.

Objective 4.4: By September 30, 2031, a minimum of 20 individuals with cognitive disabilities, requiring supports based on moderate-to-severe functional levels, at a Grade 2 to 3 reading level or below will increase their knowledge and begin to participate in public advocacy activities and/or cross disability leadership coalitions.

Key Activity 4.4.1: Implement a Partners in Policymaking curriculum strand specifically for individuals with I/DD.

Key Activity 4.4.2: Develop and implement collaboration, dissemination, sustainability, monitoring, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders that support Partners in Policymaking curriculum strand participants.

Priority Area #5: Emerging/Emergency Needs

Stability in Changing Conditions

The Florida Developmental Disabilities Council, Inc. recognizes that emerging national and state-level issues may arise that impact I/DD individuals and their families. As conditions change, their abilities to live safely in their homes and be included in their communities could be influenced in a way that necessitates a quick response.

The FDDC will remain alert to emergent and emergency needs and will pursue the proper actions that work to improve systems and ensure essential support remains available to persons with intellectual and developmental disabilities who may be negatively impacted by unforeseen circumstances.

What We Learned from Our Communities

Past and emerging concerns include:

- Advocacy for better interagency collaboration at the process and policy level
- Examination and potential advocacy for improvements to the point of entry process for disability services across agencies
- Accountability of agencies for financial resources
- Prompt corrective action when service delivery failures occur
- Concern for lack of funding for services and supports for current and future programs.
- Medicaid Waiver waiting lists and frustration with the waiver process
- Poor communication with lead agencies

Key Informants expressed concerns regarding the “availability of reliable system(s) of care” that can remain operational for both the self-advocate and the caregiver during times of crisis

“Three-year budget projections point approximately \$9 billion dollars in shortfalls in critical service areas which include health care services, education, and Medicaid spending—all impacting persons with I/DD and their families and caregivers.”
– Key Finding



Efforts to improve Florida’s service system for individuals with I/DD have continued; however, public input has reflected that demand for support is still outpacing available capacity. Concerns relating to waiver access, workforce capacity, interagency coordination, and service availability persist, and this will require systems change at the federal, state, regional, and local levels.

Priority Area: EMERGING/EMERGENCY NEEDS

Goal 5: Community inclusion for individuals with I/DD will be maintained/improved through systemic changes and/or provision of essential services and supports at the state, regional, or local level.

Objective 5.1: By September 30, 2031, one (1) or more emerging/emergency needs of individuals with I/DD will have been addressed through one (1) or more systemic changes and/or provisions of essential services and supports at the state, regional, or local level.

Key Activity 5.1.1: Develop and implement collaboration, dissemination, sustainability, communication, new resources and/or updates to existing resources, and advocacy activities in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address needed changes to statutes, rules, policies, procedures, practices, and/or funding/staffing issues (e.g., activities supporting individuals with I/DD and their families during natural or manmade disasters) that improve outcomes for individuals with I/DD.

Key Activity 5.1.2: Develop and implement the provision of essential services and supports at the state, regional, or local level to maintain/improve safe community inclusion of individuals with I/DD during emerging or emergency situations (e.g., natural or manmade disasters).

ABOUT THE STATE PLAN

Every five years the Administration for Community Living under the Developmental Disabilities and Bill of Rights Act of 2000 requires Councils to conduct a comprehensive review and analysis of statewide needs and issues faced by persons with intellectual and developmental disabilities, families, and those who support them.

Over an 18-month period beginning August 1, 2024, the Florida Developmental Disabilities Council, Inc., in partnership with WellFlorida Council, Inc., conducted extensive research and strategic planning to complete a comprehensive needs assessment, facilitate focus groups, and engage key stakeholders. This collaborative process informed the development

of the next five-year State Plan covering October 1, 2026 through September 30, 2031. Through rigorous data analysis and alignment with the priorities established by the Administration for Community Living, the Council identified five strategic priorities designed to drive systems change, influence policy, and build capacity within existing and emerging service delivery systems for individuals with I/DD and their families.

CALL TO ACTION

Visit fddc.org to track our progress, learn more about the partners who make our work possible, and join our efforts.

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