



Florida Developmental Disabilities Council, Inc.  
**Five-Year State Plan 2022-2026**





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 have existed for more than 50 years.

The main purpose of Florida's 30-member Governor appointed Council is to leverage federally appropriated dollars to facilitate major systems change, affect policy, build capacity within existing

and future delivery systems, and advocate with, and on behalf of, individuals with intellectual and developmental disabilities.

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

The Council's priorities emerged from national and state-wide data and stakeholder input from persons with intellectual and developmental disabilities, their families, and the people who support them.



# Priority Area #1: Access to Services

## Connect Florida's Individuals with Intellectual and Developmental Disabilities and Their Families to Services and Resources

There is currently no clearinghouse to connect individuals of all ages to services and programs. This void necessitates the creation of a way for individuals and families to locate and access alternative resources.

The FDDC is dedicated to addressing the gap created by multiple, existing information and resource platforms and directories. In response we will establish public-private partnerships to develop the Access to Services through Knowledge (ASK) information and resource delivery system, a web-based platform to focus on local, community resources identified and used by families.

### What We Learned

Self-Advocate and Caregiver/  
Family Member Surveys:

*Only 25% said "yes, they know what services they can get"*

*Only 20% said it was "easy to get the services they need"*

*There is a lack of "availability of services and transition into other services across the lifespan of a person with I/DD"—Key Informant Interview*

*"...the biggest issue, I think again would be information. Making sure that people that are here to support people with disabilities are really aware of all the services that the state offers."—Partners in Policymaking Focus Group*

*"There are a multitude of organizations that provide self-advocates with services but these groups do not have a unified message across the spectrum of I/DD"—Key Informant Interview*



The estimated prevalence of intellectual and developmental disabilities in Florida for 2018 is 430,393 individuals—295,528 children 0-17 years and 134,864 adults 18 and older. National data reported increases in diagnoses of I/DD among children by 7.4% from 2009 to 2017. Increases by specific diagnoses among children included: attention-deficit/hyperactivity disorder (11.8%), autism spectrum disorder (127.3%), and intellectual disability (33.3%).

## Priority Area: ACCESS TO SERVICES

**Goal 1:** Individuals with intellectual and developmental disabilities (I/DD) and their families will have knowledge of and increased access to community resources and services across the lifespan.

**Objective 1.1:** By September 30, 2026, an Access to Services through Knowledge (ASK) information and resource delivery system for the community of people with intellectual and developmental disabilities of all ages will be established through a collaborative with the Developmental Disabilities (DD) network partners and effectively utilized by a minimum of 150 family members statewide.

**Key Activity 1.1.1:** Establish a steering committee comprised of the Council, the Mailman Center at the University of Miami, the Florida Center for Inclusive Communities at the University of South Florida, and Disability Rights Florida who will contribute to all facets of the service delivery system.

**Key Activity 1.1.2:** Plan and conduct the ASK state-wide research project designed to identify key community resources across the lifespan.

**Key Activity 1.1.3:** Identify and update or develop an interactive ASK web-based platform of key community resources for families through state-of-the-art technology in a user-friendly format.

**Key Activity 1.1.4:** Plan and conduct online or onsite state-wide utilization training for family members, support coordinators, case managers and others deemed appropriate on the new online ASK system.

**Key Activity 1.1.5:** Develop and implement advocacy and communication efforts in conjunction with Florida's self-advocates, family members, and other key stakeholders to address systems change efforts that improve outcomes for individuals with intellectual and developmental disabilities.



# Priority Area #2: Home- and Community-Based Delivery Systems

## A Quality-of-Life Issue

Medicaid Home-and Community-Based Services allow for individuals with I/DD and their families to access the services and supports needed to live outside of an institution and in a setting of their choice.

Knowing what to look for and what is best for the person with I/DD, as needs emerge, is critical to ensure that the best living environment is chosen where services are delivered.

The FDDC will evaluate both case management and service delivery systems, and will develop quality measures and standards that families and organizations can use.

Access to a qualified pool of available well-trained direct support professionals is critical to ensure persons with I/DD remain in the most integrated setting possible. Furthermore, access to qualified personnel and services for person with I/DD who have severe behavior issues, with or without a mental health diagnosis, is essential to remaining out of an institutional setting.

The FDDC will focus on the development of a pool of certified direct support professionals that families and individuals can access whether receiving state funded Medicaid or using privately funded resources. In addition, the FDDC will focus on improving access to services for individuals who have a dual diagnosis of Mental Health (MH) and I/DD and develop training on effective practices.

## What We Learned

*About 50% of Self-Advocate and Caregiver/Family Member Survey respondents said they “do not get the services they need.” Unmet needs were found in:*

*Community support services (59.3%)*

*Therapies (33.9%)*

*Employment opportunities and job training (32.2%)*

*Recreational opportunities (32.2%)*

*“There is no reason why the state cannot put out information on the website about all provider types and a ranking based on their quality assurance reviews—similar to what AHCA does for nursing homes.”—Aging Caregivers Focus Group*

*As of February 2020, there were 22,865 persons on the Agency for Persons with Disabilities (APD) wait list for Medicaid Home-and Community-Based Services called iBUDGET.*



Only about 6% of caregiving families in Florida receive support from Florida’s Agency for Persons with Disabilities.

Florida ranks 49th out of 50 states in fiscal effort for spending for persons with intellectual and developmental disabilities on services and supports.

## Priority Area: HOME- AND COMMUNITY-BASED DELIVERY SYSTEMS

**Goal 2:** Individuals with intellectual and developmental disabilities (I/DD) will have increased access to personal support and behavioral services throughout Florida to provide the level of support and care required to maintain a safe quality of life.

**Objective 2.1:** By September 30, 2026, a minimum of 150 individuals with I/DD will have increased access to, and availability of, personal support service providers and behavioral services across the lifespan that allow them to remain in their homes and communities.

**Key Activity 2.1.1:** Establish and fully implement a best practice, quality case management system.

**Key Activity 2.1.2:** Establish and implement a system that allows individuals with I/DD and families to access services via a provider pool that includes individuals certified to provide personal care, companion, and/or respite services in the State’s billable categories.

**Key Activity 2.1.3:** Develop and implement advocacy and communication efforts in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve outcomes.

**Objective 2.2:** By September 30, 2026, the provision of quality services for individuals with I/DD who have significant behavioral issues will be improved in a minimum of one environment and/or setting where they are served.

**Key Activity 2.2.1:** Conduct research and develop quality measures that lead to the provision of services in all environments and/or settings where individuals with I/DD are served.

**Key Activity 2.2.2:** Establish a collaborative task force between one or more universities and applied behavior analysis (ABA) therapists to identify and address unmet needs and ensure quality services through improved access to ABA therapists in all Florida counties.

**Key Activity 2.2.3:** Develop and implement advocacy and communication efforts in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve outcomes.

**Objective 2.3:** By September 30, 2026, effective practices for a minimum of 50 individuals with significant behavioral challenges will be in place to address the targeted disparity of individuals with a dual diagnosis (i.e., developmental disability and mental health) being placed in unnecessary and restrictive settings (i.e., hospitals, institutions, and inpatient programs).

**Key Activity 2.3.1:** Investigate the dual diagnosis issue as an unmet need to prevent unnecessary interventions, ensuring that an agency and stakeholder collaborative group provides oversight and convenes to plan implementation of recommendations to improve service delivery for individuals with intellectual and developmental disabilities (I/DD) and mental health (MH) diagnoses and/or in crisis.

**Key Activity 2.3.2:** Provide training to first responders, medical personnel, and mobile crisis units on mental health and I/DD, including characteristics, and effective practices for interacting with individuals with mental health and developmental disabilities.

**Key Activity 2.3.3:** Develop and implement advocacy and communication efforts in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve outcomes.

## Priority Area #3: Aging Caregivers

### An Imminent Cliff

A large percentage of persons aging with I/DD in Florida live at home with family members, who are also aging. Compared to other states, Florida has the highest percentage of persons on a waiting list for Medicaid Home- and Community-Based Waiver services. Caring for a person at home impacts the entire family.

Aging caregivers, an aging population of adults with I/DD, and a significant shortfall of long-term care funding, both individually and collectively, is of imminent concern for individuals with I/DD and family caregivers.

The FDDC will work to create a sustainable partnership between the developmental disability and aging networks. This network will create a system of care that is both sensitive to and available for caregivers and individuals with an I/DD who are growing older.

### What We Learned

*Florida's I/DD population is disproportionately older than the national average, and thus, so are our caregivers and family members. Caregiving can be tiring for all but even more so for those caregivers that are aging themselves. This generates the question among caregivers, "What will happen to my loved one when I am no longer around or am incapable of caregiving at the level needed?"—Key Informant Interview*

*Caregiver Needs from Self-Advocate and Caregiver/Family Member Survey:*

*Meeting other families with persons with I/DD (35.1%)*

*Respite care (29.7%)*

*Healthcare for persons with I/DD (26.4%)*

*Locally-based community services (25.1%)*

*Parents and caregivers do not fully understand the aging issues of their loved ones with I/DD and the services available as they both age.—Key Informant Interview*



In Florida, 75% of persons with I/DD live with a family caregiver. Of those, 36% of persons with I/DD live with family caregivers between the ages of 42-59 and 31% of persons with I/DD live with an aging caregiver (aged 60+).

Florida has the highest percentage of all states of persons on a waiting list for services.

### Priority Area: AGING CAREGIVERS

**Goal 3:** Establish a sustainable interagency collaborative between the intellectual and developmental disabilities (I/DD) and aging networks, addressing the aging of both individuals and families that will increase their access to services and supports.

**Objective 3.1:** By September 30, 2026, a minimum of 50 individuals with I/DD and/or their families will report increased access to services or supports through research and planning, training, and systemic changes supported by an aging and I/DD network that operates as a seamless service delivery and support system.

**Key Activity 3.1.1:** Convene and facilitate key stakeholder groups to include a state level coalition, collaborative team, and grassroots level group for Florida's Aging Caregivers Initiative, who will work toward systemic changes to improve services and supports provided by both networks.

**Key Activity 3.1.2:** Conduct a study at the state and national levels to identify promising practices in providing services and supports to individuals with I/DD and their families throughout the aging process.

**Key Activity 3.1.3:** Develop and deliver cross network collaborative training to minimally include agency and organization staff, providers, individuals with I/DD, parents, siblings, caregivers, and grandparents serving as primary caregivers.

**Key Activity 3.1.4:** Develop and implement advocacy and communication efforts in conjunction with Florida's self-advocates, family members, and other key stakeholders to address systems change efforts that improve outcomes for individuals with I/DD.



# Priority Area #4: Self-Advocacy Leadership

## Empowering Persons with Intellectual and Developmental Disabilities

Advocacy is a critical component to facilitate systems change and educate decision makers about the needs and issues facing persons with I/DD (i.e., self-advocates) and their families. Creating strong and knowledgeable leaders among individuals with I/DD and family members to influence policymaking, public and private board/community involvement, and leading/educating others is critical to the I/DD movement, and a fundamental focus of the FDDC and our federal partners.

The FDDC will increase the number of self-advocates who are trained as effective leaders to impact policy through Florida's state-wide, self-advocacy organization called Florida Self-Advocates Network'D (SAND) and educate families through the Partners in Policymaking national curriculum.

### What We Learned

*"Without the support of my parents, I would be in a group home. I don't want to be in a group home."*—Self-Advocate Focus Group

*"And the biggest issue with self-advocates is they're not listened to in many cases. Because in many cases, they're segregated and so the families and other support people who believe that they should be listened to can't be there to support what they're saying. So, I just – there's more need for advocacy training not only for caregivers, family members and self-advocates, we're a group of people that all need to be talking in unison."*—Aging Caregivers Focus Group

*"I think that advocacy is so important to make sure that everybody has access to all the same things and how that looks is going to be different for everybody."*—Partners in Policymaking Focus Group



Only 48.7% of self-advocate survey respondents said they "get all the services they need."

In the past 2 years, 59.3% of self-advocates report having unmet needs for community support services; 33.9% had unmet needs for therapies; 32.2% had unmet needs for employment opportunities and job training, and an equal 32.2% had unmet needs for recreational opportunities.

## Priority Area: SELF-ADVOCACY LEADERSHIP

**Goal 4:** The number of individuals with intellectual and developmental disabilities (I/DD) active in Florida's state self-advocacy organization, trained as leaders and providing leadership training, and engaged in leadership roles will be increased.

**Objective 4.1:** By September 30, 2026, the state self-advocacy organization will increase the number of leaders trained and providing leadership training by 80%.

**Key Activity 4.1.1:** Establish baseline data on the state self-advocacy organization.

**Key Activity 4.1.2:** Utilize the Fellows Program model to train new "Fellows" to assume leadership skills in developing and delivering training to other self-advocates.

**Key Activity 4.1.3:** Conduct regional and/or state-wide training activities for other self-advocates.

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

**Key Activity 4.1.5:** Manage the state-wide self-advocacy organization.

**Objective 4.1:** By September 30, 2026, a minimum of 200 dedicated policy 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, cross disability, and culturally diverse settings.

**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 influencing policy.

**Key Activity 4.2.2:** Develop a Partners in Policymaking curriculum strand specifically for individuals with I/DD.

## About

### Florida Self-Advocates Network'D

Florida Self-Advocates Network'D (FL SAND) is an independent 501(c)(3) organization formed to expand the self-advocacy movement in Florida. It works through the support of local grassroots efforts, legislative platforms, networking with local business and civic communities, raising awareness, and promoting inclusion for all. FL SAND provides a united voice on statewide issues and topics that are important to self-advocates and all persons with developmental disabilities throughout the state.  
<https://www.flsand.org>

### Partners in Policymaking

Partners in Policymaking® (PIP) is a leadership training program that prepares adults with intellectual and developmental disabilities (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.  
<https://www.fddc.org/partners-in-policymaking/>

# Priority Area #5: Broad Systems Change and Emerging Needs



While the Florida legislature has recently acknowledged and increased funding for the Agency for Persons with Disabilities to specifically serve persons with I/DD, overcoming long-term gaps, addressing population growth, rising costs, and workforce issues will be a continuing challenge requiring system change and collaboration among federal, state, regional, local and community partners.

## Collaboration and Inclusion

The Florida Developmental Disabilities Council, Inc. is charged with keeping a finger on the pulse of national and state-wide issues facing persons with I/DD and their families as they emerge and evaluating their impact on keeping individuals out of institutional settings.

The FDDC will continue to analyze existing systems and policies that impact inclusion of persons with intellectual and developmental disabilities in their communities and watch for emergent issues that negatively impact our constituency and our mission.

## What We Learned

*It is difficult to predict what issues might emerge over a five-year period; however, past issues have included:*

*Aging caregivers*

*Pandemic impact on caregiving*

*Co-occurring mental health issues among the I/DD population*

*Disaster preparedness and recovery*

—Key Informant Interviews

*“I wish that they could have a service where they had people that were knowledgeable [about] not just one part of the system...you need people who are knowledgeable in the entire system to sit down with you and let you know what all your options are. And what you’re eligible for in everything so that you know what you’re getting into.”—Self-Advocate Focus Group*

## Priority Area: BROAD SYSTEMS CHANGE/EMERGING NEEDS

**Goal 5:** Community inclusion for individuals with intellectual and developmental disabilities (I/DD) will be increased by systemic changes at the state, regional, or local level.

**Objective 5.1:** By September 30, 2026, one (1) or more emerging needs of individuals with I/DD will have been addressed through one (1) or more state, regional, or local level systemic change.

**Key Activity 5.1.1:** Develop and implement advocacy and communication efforts in conjunction with individuals with I/DD, family members and other key stakeholders to address needed changes to statutes, rules, policies, procedures, practices, and/or funding/staffing issues that improve outcomes for individuals with I/DD.

**Objective 5.2:** By September 30, 2026, a minimum of six state, regional, or local level systemic changes will have been achieved that improve the lives of individuals with intellectual and developmental disabilities.

**Key Activity 5.2.1:** Complete implementation of initiatives started in the 2017-2021 state plan and report on systems change outcomes resulting from the work completed.

**Key Activity 5.2.2:** Develop and implement advocacy and communication efforts in conjunction with Florida’s self-advocates, family members, and other key stakeholders to address systems change efforts that improve outcomes for individuals with I/DD.

#### **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 the past 18 months, the Florida Developmental Disabilities Council, Inc. in partnership with WellFlorida Council, Inc. conducted the research to complete a comprehensive needs assessment, conduct focus groups and meet with key stakeholders to create the

next five-year state plan (October 2021-September 2026). Through data analysis combined with addressing the key priorities set forth by the Administration for Community Living, the Council has identified five priorities that will create systems change, affect policy, and/or build capacity within existing and future delivery systems for persons with I/DD and their families.

#### **CALL TO ACTION**

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





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