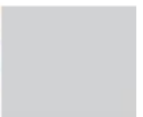




Five-Year State Plan 2022-2026 Comprehensive Review and Analysis

State Plan Development, Consulting Agreement #5030AMD19



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Executive Summary

STATEMENT OF PURPOSE

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402), colloquially known as the “DD Act,” requires each state to establish and maintain a developmental disability (DD) Council. In response, the Council, along with a designated state agency whose purpose is to support the Council’s efforts, are to work together in the creation of the five year state plan. The state plan must be developed at the hand of data-driven strategic planning, inclusive of a review of progress; identification of needs based on data analysis and review; and the development of goals based on the collected data.

More specifically, data analysis and review should thoroughly discuss the unmet needs of persons with intellectual and developmental disabilities (I/DD), as well as their families and/or caregivers. The plan should address the needs of unserved and underserved populations (i.e.: racial/ethnic minorities, disadvantaged persons, persons with limited English proficiency, varying geographic regions, members of the LGBTQIA+ community, and other potential underserved groups within the population of persons with I/DD). The plan should be reflective of the state’s diversity, while also emphasizing advocacy, capacity building, and the potential for systems change.

The Florida Developmental Disabilities Council’s (FDDC) webpage, “About FDDC,” highlights the Council’s purpose as “advocating and promoting programs, practices and innovative initiatives that enhance the independence, productivity, inclusion, and self-determination of individuals with developmental disabilities in all aspects of life.” The Council has a long-standing history of utilizing federally appropriated dollars, through the DD Act, to influence policy and services for persons with I/DD.

In an effort to conduct the Comprehensive Review and Analysis for the 2022-2026 State Plan, the Council contracted WellFlorida Council, Inc.

PROCESS

The comprehensive assessment and strategic planning process started in October 2019 and concludes with this report in June 2021. WellFlorida collected primary and secondary data to complete analyses regarding the availability and quality of services for persons with I/DD, as well as their families. The primary data analyses included: focus groups with Partners in Policy Making (PIP), self-advocates, and aging caregivers; key informant interviews with agency leaders and professionals working in the I/DD community; and surveys for self-advocates and their families/caregivers. Secondary data was collected

from a multitude of reports from various sources, including, but not limited to national agencies, Florida state agencies, and regional/community state agencies. Some of the secondary data sources reviewed were only available at a statewide level. However, WellFlorida was able to partition and analyze some data at both the county and regional levels; in certain cases, there is an inclusion of an urban versus rural divide. Secondary data on the I/DD population is limited, as such, secondary data on persons with disabilities is often utilized. Secondary data sources referring to “persons with a disability” include all types of disabilities, not only I/DD. It is important to note that the definitions for persons with intellectual and developmental disabilities are inconsistent amongst data sources. For the purposes of this report, “intellectual disability” starts any time before a child turns 18 and is characterized by problems with both:

- Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve and other skills; and
- Adaptive behavior, which includes everyday social and life skills.

For the purposes of this report, “developmental disabilities” is a broader category of often lifelong disability that can intellectual, physical or both (National Institutes of Health , 2016).

Furthermore, in keeping with the Council’s recommendation, the state’s 67 counties were separated into six different Regions:

- Northwest Region (16 Counties): Bay, Calhoun, Escambia, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Okaloosa, Santa Rosa, Wakulla, Walton, and Washington.
- Northeast Region (20 counties): Alachua, Baker, Bradford, Clay, Columbia, Dixie, Duval, Flagler, Gilchrist, Hamilton, Lafayette, Levy, Madison, Nassau, Putnam, St. Johns, Suwannee, Taylor, Union, and Volusia.
- Central Region (12 Counties): Brevard, Citrus, Hardee, Hernando, Highlands, Lake, Marion, Orange, Osceola, Polk, Seminole and Sumter.
- Suncoast Region (11 Counties): Charlotte, Collier, DeSoto, Glades, Hendry, Hillsborough, Lee, Manatee, Pasco, Pinellas and Sarasota.
- Southeast Region (6 Counties): Broward, Indian River, Martin, Okeechobee, Palm Beach and St. Lucie.
- Southern Region (2 Counties): Miami-Dade and Monroe.

Counties were separated into Rural or Urban Counties, and where possible, data was analyzed according to Rural or Urban Counties:

- Rural Counties (32 Counties): Baker, Bradford, Calhoun, Columbia, DeSoto, Dixie, Flagler, Franklin, Gadsden, Gilchrist, Glades, Gulf, Hamilton, Hardee, Hendry, Highlands, Holmes, Jackson, Jefferson, Lafayette, Levy, Liberty, Madison, Nassau, Okeechobee, Putnam, Suwannee, Taylor, Union, Wakulla, Walton and Washington.
- Urban Counties (35 Counties): Alachua, Bay, Brevard, Broward, Charlotte, Citrus, Clay, Collier, Duval, Escambia, Hernando, Hillsborough, Indian River, Lake, Lee, Leon, Manatee, Marion, Martin, Miami-Dade, Monroe, Okaloosa, Orange, Osceola, Palm Beach, Pasco, Pinellas, Polk, St. Johns, St. Lucie, Santa Rosa, Sarasota, Seminole, Sumter and Volusia.

Evidence-based practices were followed, under the guidance of the Information and Technical Assistance Center for Councils on Developmental Disabilities (iTACC). iTACC is a project of the National Association of Councils on Developmental Disabilities (NACDD), where NACDD serves as technical assistance to all DD Councils across the nation, as well as an advocate for national policy and leadership.

USING THIS REPORT

This report should be interpreted such that the unmet needs of persons with I/DD, driven by both the primary and secondary data, are then translated into achievable goals and objectives to reach the outcome of increased inclusivity for all persons with I/DD.

Data collected by WellFlorida can be found within the *2020 Florida Developmental Disabilities Council Statewide Comprehensive Review and Analysis: Technical Appendix*. Within this report, referred to as the *Technical Appendix* going forward in this document, the major highlights are discussed and are broken down into the following categories: State Information, Portrait of the State, Public Input, Analyses of State Issues and Challenges, Identification of Strategic Priorities and Goals, FDDC Five Year State Plan, References, and supporting material in the Appendix. In accordance with iTACC's State Plan Development Guide, all required and some optional subject areas of the aforementioned categories are covered. It is important to note that when a specific data table from the *Technical Appendix* is referenced, it is by table title and number, e.g. (Health 1, Technical Appendix); all citations are in APA format.

SUMMARY OF FINDINGS

STATE INFORMATION

More than 21 million people live in Florida and there are an estimated 336,529 persons with I/DD (Demographics Tables 1 and 10, Technical Appendix). The number of persons with I/DD grows as the

general population increases. National studies indicate that the rates of I/DD in children is increasing, however, this report utilizes a prevalence rate of 1.58 percent as recommended by the National Association of Councils on Developmental Disabilities (National Association of Councils on Developmental Disabilities, Information and Technical Assistance Center for Councils on Developmental Disabilities, 2020). The estimated prevalence of children with developmental disabilities has increased since 2009. From 2009-2011 to 2015-2017, the percent of children aged 3-17 years diagnosed with developmental disabilities rose by 7.4 percent overall, from 16.2 to 17.8 percent. There were marked increases by specific diagnoses, such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD). The diagnosis of ADHD among children for that same period rose by 11.8 percent, while ASD diagnoses grew by 127.3 percent and intellectual disabilities by 33.3 percent (Demographics Table 14, Technical Appendix).

Nationally, about 75 percent of adults with I/DD live with parents or other family members, with the majority not receiving any formal services or supports (Friedman, 2019). Approximately 20 percent of noninstitutionalized Florida residents with a disability have less than a high school degree compared to 10 percent of the noninstitutionalized Florida residents without a disability and the percentage of noninstitutionalized Florida residents with a disability with a bachelor's degree is 18.4 percent compared to 31.7 percent of noninstitutionalized Florida residents without a disability (Demographics Table 20, Technical Appendix). Just over 19 percent of Florida residents with a disability are employed compared to 62.3 percent of Florida residents without a disability (Demographics Table 21, Technical Appendix).

On average in Florida, persons with disabilities earn less than persons without a disability. Nearly 40 percent of noninstitutionalized Florida residents with a disability earn less than \$15,000 annual as compared to 13.2 percent of noninstitutionalized Florida residents without a disability (Demographics Table 22, Technical Appendix). Persons with a disability are more likely to live below the poverty level than persons without a disability in Florida and in the nation (Demographics Table 23, Technical Appendix).

PORTRAIT OF THE STATE

The Portrait of the State section describes the services, supports and other assistance available to persons with I/DD and their families and caregivers in Florida.

Healthcare

While insurance coverage does not guarantee the accessibility of services or better health outcomes, those with I/DD in Florida disparately lack the ability to utilize the health care system because they are not as frequently insured, as compared to the national average. Any type of data relevant to individuals

with private coverage is much more difficult to procure, although individuals are privately and publicly insured at similar rates. A majority of available data is reflective of all disability types, indicating that there is a need to better the collection and reporting of health data specifically for persons with I/DD.

It is imperative to note that with the implementation of the Patient Protection and Affordable Care Act (ACA), the state of Florida chose not to expand Medicaid, medical assistance program that provides access to health care for low-income families and individuals. Expanding Medicaid would have made more individuals in the state eligible for the program based on their income. Due to the lack of Medicaid expansion in Florida, Florida has a much higher percentage of individuals without insurance coverage as compared to the United States as a whole. According to the *Annual Disability Statistics Compendium: 2018*, 9.9 percent of the United States' population of persons with a disability are not insured (Health 6, Technical Appendix). However, Florida's percentage of persons with a disability with no coverage, at all, is approximately 15.8 percent (Health 6, Technical Appendix). In Florida, the percentage of persons with a disability with coverage was 84.2, while the United States was 90.1 percent (Health 6, Technical Appendix). When examining coverage types, the percentage of persons with private coverage in Florida and the US was 44.3 and 45.8 percent, respectively (Health 6, Technical Appendix). In Florida, the percentage of persons with any type of disability with private coverage was 44.3 percent (Health 6, Technical Appendix). Florida falls behind the national average in both private and publicly-funded insurance, indicating that the absence of one does not guarantee the other.

The state of Florida operates and provides health insurance coverage to approximately 3.78 million Floridians (Health 7, Technical Appendix) through its Statewide Medicaid Managed Care (SMMC) program. The SMMC program is comprised of three separate entities: Managed Medical Assistance (MMA), Long-Term Care (LTC), and Dental. As of December 2019, there were 3,779,655 Floridians enrolled in Medicaid (Health 7, Technical Appendix). The Children's Medical Services (CMS) Network, operated by WellCare, is the managed-care delivery system of Medicaid to children with special health care needs in the state of Florida. As of December 2019, 59,874 children are enrolled in the CMS plan, which includes, but is not limited to, children with I/DD.

Florida's total Medicaid expenditures have been on the rise in recent years. Between Fiscal Years 2013 and 2016, expenditures have increased from \$437,670,823 (in thousands of dollars) to \$549,308,238 (in thousands of dollars) (Health 8, Technical Appendix).

The United States' Medicaid Long-Term Services and Supports (LTSS) is a compilation of programs housed under what is known as Home and Community-Based Services (HCBS). These services are comprised of: Section 1915(c) waiver services, Community First Choice, rehabilitative services, and institutional services, such as nursing facilities and intermediate care facilities for persons with

intellectual disabilities (ICF/IID) (Eiken, 2018). The state of Florida gives persons with I/DD only two pathways to receive home or community-based care under Medicaid, either through a Section 1915(c) waiver or within an ICF/IID. As an alternative to institutionalization in an ICF/IID, Medicaid Waivers for persons with I/DD began in the early 1980s (Thach, 2018). The preference for persons with I/DD to live within their community, rather than in an institution, has continued to grow over the years.

Florida's version of the Section 1915(c) waiver, the iBudget Florida waiver, was signed into law in 2010 under the 2009-2010 General Appropriations Act (Florida Agency for Persons with Disabilities, 2012). The iBudget Florida is currently operated by the Agency for Persons with Disabilities (APD). As of October 2019, there are 34,919 persons receiving services through the iBudget (Delia, P. and Gerbrant, B., 2020).

Currently, the system utilizes individual choice, as well as the support of an individual's family/caretaker and a Waiver Support Coordinator (WSC). The WSC is responsible for overseeing the process of receiving support from the iBudget, once the individual has been accepted for services under the APD's eligibility criteria.

The Consumer Directed Care Plus (CDC+) Waiver exists as a program alternative to the iBudget (HCBS) waiver. It is a long-term care program that involves the person throughout the entire process, such that they are leading the planning of their supports and services, with greater control of the supports and services.

Although many Floridians receive services through iBudget, there is a waitlist to receive the iBudget waiver. The iBudget waitlist first reached over 20,000 persons in May of 2011. The waitlist's large and historically growing numbers are fueled by a limited budget as dictated by the Florida Legislature.

Employment

A host of agencies work towards assuring that persons with disabilities, including I/DD, can train and find placement in jobs and also receive the services and supports to maintain or improve their employment prospects. Although there are a host of agencies and programs aimed at assisting persons with I/DD find employment, Florida's rates for employment for persons with I/DD falls behind national rates. Only 10.0 percent of National Core Indicators (NCI) Florida participants reported having a paid community job compared to 18.0 percent nationwide (Employment Table 1, Technical Appendix).

The Florida Department of Education Division of Vocational Rehabilitation (VR) leads Florida's federal and state partnership efforts to help persons with disabilities prepare for, secure, and advance in jobs. In 2018-2019, VR served almost 50,000 individuals, including more than 22,000 transition-age youth.

VR assisted 5,924 Florida residents in becoming successfully employed (Florida Department of Education, Division of Vocational Rehabilitation, 2019).

Florida's Agency for Persons with Disabilities (APD) offers many programs and services to promote training and employment support for persons with disabilities. Through the iBudget Florida and Home and Community-Based Services (HCBS) Medicaid Waiver, APD offers individual and family training, as well as job supports for those in the Consumer Directed Care Plus (CDC+) program. In 2017-2018, APD reported it had placed 2,957 individuals in competitive employment, representing 5.0 percent of those served by the agency. About 9.2 percent of those receiving ADP services were in competitive employment in 2017-2018; this represents a decrease of about 18.5 percent. For that same period, APD reported that 7,682 individuals who wanted employment were not employed (Employment Table 4, Technical Appendix).

As an arm of the Department of Economic Development (DEO), Florida's 24 Local Workforce Development Boards support employers and help Floridians gain employment, stay employed, and advance in their careers. Workforce Development Boards offer career and job placement support through their disability employment specialists. For the Fiscal Year 2017-2018, DEO reported serving 41,402 persons with disabilities across Florida with 7,832 persons with disabilities placed in employment (Employment Table 7, Technical Appendix).

The mission of The Able Trust, an organization created by the Florida Legislature to support vocational rehabilitation efforts, is to provide opportunities for successful employment for Floridians with disabilities. The Able Trust has distributed more than \$41 million in grant funding for employment support for persons with disabilities in all 67 Florida counties (The Able Trust, 2018).

Only 19.0 percent of Floridians reported having community employment as a goal in their service plan, while 29.0 percent nationally strive for employment (Employment Table 1, Technical Appendix).

Post-school outcome data from the Florida Department of Education, Bureau of Exceptional Education and Student Services point to achievements for students with disabilities. In 2016-2017, of the students with disabilities who exited Florida public schools the previous year, 51.0 percent were found enrolled in higher education or competitively employed. This represents a gain of 16.0 percent in one academic year (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019).

The FDDC Council projects made important impacts in the area of postsecondary transition and employment. Instituted in 2015, Project TOPS (Transition to Postsecondary Institutions) was a three-year program at Robert Morgan Education Center and Technical College that provided supportive

strategies for students 18 to 22 years of age with I/DD. In its third year, enrollment increased to 35 students and achieved status as a Florida Postsecondary Comprehensive Transition Program by the Center for Students with Unique Abilities. The Council supports the Employ Me 1st project of the Institute for Community Inclusion, which maintains this aptly named website that provides information and links to employment-related services. There are 37 Project SEARCH sites in Florida across 26 counties.

Informal and Formal Services and Supports

People with developmental disabilities and their families and caregivers in Florida are served by numerous governmental, private, nonprofit, volunteer, and service organizations, agencies, and associations.

Florida's Agency for Persons with Disabilities (APD) is tasked specifically with serving the needs of Floridians with developmental disabilities. In addition to administering the iBudget Florida program and extensive Medicaid Home-Based and Community Services (HBCS), APD's Home and Community Services Administration provides other supports and resources. These include support coordination, adult day training services, adult and child respite services, specialized assessments and therapies along with needed equipment and supplies.

The Florida Department of Children and Families (DCF) partners with local communities to protect vulnerable populations, promotes strong families, and supports self-sufficiency, recovery, and resiliency for individuals and families.

The Children's Special Health Care section of the Florida Agency for Health Care Administration (AHCA) reports that more than 93 percent of families were satisfied with the care provided under the program in 2018-2019. AHCA is responsible for Florida's Medicaid program that serves nearly five (5) million people and licenses almost 50,000 health care facilities. Under Title XXI of the Social Security Act, State Children's Health Insurance Program (SCHIP), AHCA reports that 216,350 children were enrolled in the KidCare program in 2018-2019, with 28,089 also enrolled in the MediKids program, and 11,732 in the Children's Medical Service (CMS) Network. CMS is a division of the Florida Department of Health, offering six (6) programs for children with special health care needs. Through its Medicaid Services for individuals in 2018-2019, AHCA reports that more than two (2) million children received the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services and that 73 percent of eligible children completed the EPSDT screenings (Florida Agency for Health Care Administration, 2019).

The Florida Department of Elder Affairs (DOEA) serves more than five (5) million residents of Florida who are 60 years of age and older. Most direct services are provided through the Division of Statewide

Community-Based Services through 11 Area Agencies on Aging (also called Aging and Disability Resource Centers, ADRCs) and local service providers.

Families and caregivers of persons with I/DD may access resources and services through Healthy Families Florida, a home visiting program for expectant parents and families with newborns experiencing stressful life situations.

The Multiagency Network for Students with Emotional/Behavioral Disabilities (SEDNET) is a network of 19 regional projects working to assure the provision of quality care for students with or at-risk for emotional and/or behavioral challenges. The SEDNET regional stakeholders voice the needs of students in each school district, work to improve service coordination, and involve parents and students in local systems of care. SEDNET is funded through the Florida Department of Education (DOE), Bureau of Exceptional Education and Student Services (BEES). The Institute for Small and Rural Districts (ISRDI) is also funded through the Florida DOE BEES to provide technical assistance for positive outcomes for students with disabilities and their families in the 48 small, rural school districts in Florida (Institute for Small and Rural Districts, Florida Department of Education, Bureau of Exceptional Education and Student Services, n.d.).

The University of South Florida's Florida Center for Inclusive Communities' Positive Behavior Interventions and Support (PBIS) initiative works to enhance Florida's school district capacity to implement positive behavioral interventions within a multi-tiered system of support. The Florida Center for Students with Unique Abilities (FCSUA) at the University of Central Florida was established in 2016 to implement requirements of the Florida Postsecondary Comprehensive Transition Program Act (2019 Florida Statutes, 1004.6495, 2020). Florida's Centers for Autism and Related Disabilities (CARD) serve persons with current a diagnosis of Autism Spectrum Disorders (ASD) and related disabilities, along with their families and professionals who care for them. Seven (7) regional CARD sites are funded by the Florida Legislature through the Florida DOE. Sites include Florida Atlantic University, Florida State University, University of Central Florida, the University of Florida at Gainesville and Jacksonville, University of Miami, and the University of South Florida.

The Division of Vocational Rehabilitation (VR) of the Florida Department of Education manages the independent living program for persons with disabilities. The program provides services through a network of private nonprofit, non-residential, locally-based and consumer-controlled Centers for Independent Living (CILs). There are 16 CILs in Florida that offer four (4) categories of core services, which include: information and referral, independent living skills training, individual and systems advocacy, and peer counseling. In Fiscal Year 2018-2019, the Florida DOE reports serving 17,151 clients with disabilities with independent living services (Florida Department of Education, 2019).

Residential Options of Florida (ROOF), a nonprofit organization, was established by the Florida Inclusive Housing Task Force of FDDC. ROOF informs people with I/DD about housing options. ROOF also identified the need for tools to help with planning for independent living and navigating the often-complex housing options (Residential Options of Florida, n.d.).

The Florida Self-Advocates Network'D (FL SAND) is a statewide, nonprofit organization focused on expanding self-advocacy throughout Florida, via service as a united voice on important issues for self-advocates and all persons with I/DD. Disability Rights Florida serves persons with disabilities in Florida through advocacy, education, investigation, and litigation to protect and advance rights, dignity, equal opportunity, choice, and self-determination.

Interagency Initiatives

A shared vision and mission to improve the quality of life for persons with I/DD and their families and caregivers are at the core of each of these federally-assisted state interagency initiatives. Collaboration and cooperation are important to leverage resources, close service gaps, avoid duplication, implement best and innovative practices, promote supportive policy, and advocate for positive change for all people and communities.

Quality Assurance

The Agency for Health Care Administration (AHCA) currently contracts with Qlarant to administer the Statewide Quality Assurance Program to examine the state's developmental disabilities service system. AHCA works in partnership with the Agency for Persons with Disabilities in this endeavor. The quality assurance efforts focus on the Developmental Disabilities Home and Community-Based Services (HCBS) Waiver and the Consumer Directed Care Plus (CDC+) programs. Qlarant conducts periodic person-center reviews (PCR) and provider reviews (PDR) to examine adherence to protocols and aspects of customer service satisfaction. The PCR consists of an interview with the person with a disability, the person's support coordinator, and a review of records maintained by the support coordinator. The components of a PDR include an individual interview, staff interview, observations, service-specific records review, policies and procedures review, and qualifications and training review. Qlarant's third-quarter report, published in May 2018, showed that average scores on all review components (interviews, observations, and records reviews) were at 90 percent or higher. The review identified issues with providers having policies in place for background screening procedures (about 19.0 percent of providers reviewed), and 16.0 percent of providers had elements missing from the required documentation for at least one employee. Qlarant hosts online resource centers for individuals and families and providers, supplies a training center, and convenes an in-person quality council (Qlarant, 2018).

Persons with I/DD, their families and caregivers can turn to various state agencies and organizations for supports and services related to the prevention of abuse, neglect, exploitation, inappropriate use of restraints and seclusion, and violations of human rights. The Florida Department of Child and Families' (DCF) Abuse Hotline fielded almost half a million calls in Fiscal Year 2018-2019. During that same timeframe, DCF conducted nearly 50,000 investigations, including those that examined potential cases of abuse, neglect, or exploitation of persons with disabilities and the frail elderly.

Education and Early Intervention

Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. Infants and toddlers, birth through age 2, with disabilities and their families receive early intervention services under IDEA Part C. Children and youth ages 3 through 21 receive special education and related services under IDEA Part B.

The Florida Department of Health Children's Medical Services (CMS) Early Steps is an umbrella program that assists families with high risk or developmentally delayed infants and toddlers obtain the services they need. The program identifies infants early, develops Individualized Family Support Plans (IFSP), and coordinated early intervention services and supports. IDEA Part C program services fall under the Early Steps umbrella. In 2019 there were about 57,000 children active in the Early Steps program (Health Table 53, Technical Appendix).

The Children's Forum and Florida's Office of Early Learning sponsor the Help Me Grow Florida program in 31 Florida counties. This program provides free developmental and behavioral screenings for children up to eight (8) years of age and connects families to services. Since 2014, Help Me Grow Florida facilitated 23,434 developmental screenings, made 19,437 referrals, and served 23,147 children (Help Me Grow Florida, 2019). There are 30 Early Learning Coalitions throughout Florida that provide services such as Voluntary Prekindergarten (VPK), school readiness, and childcare resource referrals.

IDEA Part B special education and education services for school-aged children from three (3) to 21 years of age are provided by Florida Department of Education, Bureau of Exceptional Education and Student Services (BEES). For the school year 2017-2018, there were 349,764 students aged 6 through 21 years who received Part B services in Florida schools. According to the 2019 State Education Agency (SEA) Profile, 14.0 percent of students pre-kindergarten through 12th grade population were students with disabilities. Students with intellectual disabilities represent about 7.1 percent of all students with disabilities (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019).

In 2018-2019, about 76.0 percent of students with disabilities were in regular classes (i.e., spent 80.0 percent or more of the school week with students without disabilities) and 14.0 percent were in separate classes (i.e., spent between 40.0 and 80.0 percent of the school week with students without disabilities). The standard diploma graduation rate in 2017-2018 for Florida students with disabilities was 80.0 percent, a notable increase of 21.2 percent from approximately 66.0 percent in 2016-2017. The dropout rate for students with disabilities fell to 13.0 percent in 2017-2018 from 17.0 and 16.0 percent in 2015-2016 and 2016-2017, respectively. Post-school outcome data in 2016-2017 show 24.0 percent of Florida students with disabilities who exited school the previous year were enrolled in higher education, 51.0 percent were enrolled in higher education or were competitively enrolled, and 59.0 percent were enrolled in higher education or some other postsecondary education or training program or competitively employed (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019).

According to BEESS in 2016-2017, when examined by exceptionality, students with emotional/behavioral disabilities (EBD) were involved in the most incidents of use of restraints at 42.0 percent and seclusion at 55.0 percent, followed by students with Autism Spectrum Disorder at 24.0 percent and 18.0 percent, respectively. In that school year statewide, there were 8,700 restraint incidents involving 3,239 students and 1,351 seclusion incidents involving 503 students. Restraint use increased by about 14.0 percent from the previous school year, while seclusion incidents decreased by an almost equal percent at 13.6 percent (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2017).

In 2016-2017, 93.4 percent of Florida teachers employed to work with students receiving special education under IDEA Part B were classified as highly qualified; this is on par with the national figure of 93.2 percent (Education Table 13, Technical Appendix).

In 2016, the Florida Governor signed into law the Florida Postsecondary Comprehensive Transition Program Act (FPCTP), which expands inclusive and experiential postsecondary education and employment for students with intellectual disabilities through degree, certificate, or non-degree programs. As a result, the Florida Center for Students with Unique Abilities was established at the University of Central Florida. There are more than 100 institutions of higher education throughout Florida, offering services and programs through the FPCTP to students with disabilities (Florida Center for Students with Unique Abilities, n.d.).

Housing

The shortage of affordable, safe housing has been a persistent issue in Florida. More than 35 years ago, the state Legislature created the Florida Housing Finance Corporation (also known as Florida Housing)

to provide a range of affordable housing options and opportunities. Multifamily development includes incentives for the development of rental housing, loans and mortgage bond programs, elderly housing community loans, low-income tax credits, and grants to serve persons with I/DD. The State Housing Initiatives Partnership (SHIP) makes funds available to local governments to form partnerships that preserve and create affordable homes and multifamily housing. SHIP dollars are distributed to all 67 counties and 52 community development block cities in Florida, where they are invested in housing assistance programs and policy and ordinance development. SHIP funds can fund emergency repairs, new construction, rehabilitation, fees, financing, matching dollars for federal housing programs, and homeownership counseling.

A confluence of factors drives the housing decisions of persons with I/DD and their families and caregivers. Housing affordability may be among the top factors individuals and families deal with. As reported earlier, almost 16 percent of Floridians live at or below the Federal Poverty Level and the incomes of persons with disabilities and without disabilities lag behind national figures (Demographics Table 22, Technical Appendix). Residents in rural Florida counties have higher rates of poverty than those in the 35 urban counties (Demographics Table 8, Technical Appendix). In Florida, more than 86 percent of persons with I/DD who live in individualized settings live in a family home (Demographics Table 15, Technical Appendix). In 2017, the average Supplemental Security Income (SSI) monthly payment for Floridians was \$773, which did not cover the average rent for a one-bedroom apartment, starting at \$850 (Housing Table 2, Technical Appendix); (Schaak, 2017).

A recent national study found that about 75.0 percent of adults with I/DD live with a parent or caregiver and are not connected to services and supports available through public programs. Five (5) factors ranked as the most important to persons with I/DD when deciding where to live included: safety, security and freedom from crime; cost; location; proximity to family; and quality of services and supports. The dream home setting of 61.8 percent of study participants was their own home or apartment, followed by a supervised group home (14.4 percent) and home of family member or friend (11.9 percent) (Housing Table 9, Technical Appendix); (Friedman, 2019).

Transportation

Created by the Florida Legislature in 1989, the Commission for the Transportation Disadvantaged develops policies and procedures for the coordination of transportation services the transportation disadvantaged. The Commission is assigned to the Florida Department of Transportation for administrative and fiscal accountability. Through the establishment of a planning agency for each service area and relationships with Community Transportation Coordinators (CTC), the Commission assures that local planning is aligned with its mission and that transportation disadvantaged riders receive services. Per Florida Statute 427.011, transportation disadvantaged funds may be used for:

planning, Medicaid transportation, administration, operation, procurement and maintenance of vehicles, and capital investments. The statute stipulates that paratransit consists of those elements of public transit which provide service between specific origins and destinations as selected by the individual rider with service being provided at an agreed-upon time. Paratransit services can be provided by taxis, limousines, dial-a-ride services, buses, and other arrangements classified as demand-responsive with non-fixed route operations. Riders include older adults, persons with disabilities (physical or developmental), people with low income, and at-risk children. Chapter 427 Florida Statutes and Commission guidelines are used to determine rider eligibility, which must be established before services can be provided. The Americans with Disabilities Act (ADA) requires that public transit systems be accessible to individuals with disabilities. The ADA mandates that public transit entities that provide fixed-route rail or bus services also provide complementary paratransit services. However, individuals with disabilities must apply and be deemed eligible for paratransit services. The eligibility process is determined by the transit system as described above.

Statewide from 2017-2018, almost three (3) million trips were provided for persons with disabilities (Transportation Table 2, Technical Appendix). The highest percentage of unmet trip requests in Florida were related to employment and medical care. Unmet trip requests were higher in rural counties (Transportation Table 7, Technical Appendix).

Childcare

Early care services, along with before- and after-school care services, are concerns for persons with I/DD and their families and caregivers. The U.S. Department of Health, and Human Services, Administration for Children and Families, Office of Child Care serves as a starting point in the search for quality, affordable childcare for a child with a disability (HHS, Administration for Children and Families, Office of Child Care , n.d.). Florida has three Parent Training and Information Centers (PTI) and two Community Parent Resource Centers (CPRC) that provide information and support services. The Florida Department of Children and Families (DCF) regulates childcare providers and offers resources for choosing a child care provider (Florida Department of Children and Families, n.d.). The Florida Department of Education Office of Early Learning offers guidance and referrals for finding quality childcare. Through the Family Caregiver Support Program, the Florida Department of Elder Affairs provides child day care and/or sitter services for a child under 18 years of age with a disability living with a grandparent. The agency reports having provided 8,877 hours of day care services and 16,047 hours of sitter services for the Fiscal Year 2018-2019 (Services Table 4, Technical Appendix).

Families of children with disabilities face challenges with childcare, according to a 2020 study. More than one-third (34.0 percent) of parents of children with disabilities report having difficulty finding childcare, compared to 25.0 percent of parents of children with no disabilities. About 34 percent of

parents of children with disabilities report not being able to find care, while 29.0 percent of parents of children with no disabilities report not finding care. Among the almost two-thirds (66.0 percent) of parents of children with disabilities who did find care, many had to rely on a patchwork of childcare comprised of paid care, family and friends covering care, and parents missing work. Relatedly, the parents of children with disabilities were found to be three (3) times more likely to experience job disruptions (e.g., arriving late, leaving abruptly or early, needing time off, and/or requesting schedule changes) because of childcare issues (Novoa, 2020).

Recreation

In Florida, there is a variety of organizations that support and promote recreation services for persons with disabilities. These include the Florida Disabled Outdoors Association, Florida Special Olympics, and the Florida State Park Service, along with its national counterpart, the National Park Service, and local (county and city) parks and recreation agencies. Special Olympics Florida serves about 58,000 athletes and has more the 38,000 coaches and volunteers. They offer ongoing training and sports competitions in 11 fall and summer sports categories with a complement of additional competitions offered at various county and local levels. Special Olympics Florida brings their Unified Champion Schools education program to public schools and offers the Healthy Athletes program to Special Olympic athletes to improve and maintain fitness. Little ELITES (Elementary Level Introduction to Entry-level Sports) guides young athletes from ages 2 to 7 years into the Special Olympics program for those 8 years of age and older (Special Olympics Florida, n.d.).

PUBLIC INPUT

Quantitative data from a vast array of secondary or administrative data sets in part describe the core issues and needs of persons with I/DD and their families and caregivers in Florida. The perspectives and opinions of self-advocates, their caregivers, providers, and agency leaders are essential to fully understanding the landscape and architecture of Florida's system of supports and services for persons with I/DD. For a diverse representation of Florida's population of persons with I/DD and those who care for them, the assessment sought public input through two phases of public input. WellFlorida Council worked with the Florida Developmental Disabilities Council to identify the types of public input (surveys, key informant interviews, and focus groups) and the populations of interest for each (Partners in Policymaking, Self-Advocates, Caregivers/Family Members, and Key Informants).

Phase I included the following:

- Focus Groups with Partners in Policymaking
- Self-Advocate Survey
- Caregiver/Family Member Survey

- Key Informant Interviews

Data collected for Phase I occurred from February 2020 – May 2020.

At the completion of the Phase I data collection, WellFlorida Council and the Florida Developmental Disabilities Council continued to receive public input through two additional focus groups with self-advocates and aging caregivers. These additional focus groups were utilized as a means to learn more about the issues facing self-advocates and aging caregivers. Issues related to aging caregivers was a topic of discussion among Council members, key informants, and Partners in Policymaking focus group participants which led to the facilitation of a focus group with aging caregivers. Furthermore, aging caregiver issues were relevant in secondary data findings. To better understand issues facing aging caregivers, WellFlorida Council and the Florida Developmental Disabilities Council facilitated a focus group with aging caregivers.

Phase II included the following:

- Focus Groups with Self-Advocates
- Focus Groups with Aging Caregivers

Data collected for Phase II occurred from June 15 – July 2020.

Focus Groups with Partners in Policymaking

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to develop a focus group script used with advocates from Partners in Policymaking. The focus group script was comprised of eleven (11) questions regarding: Advocacy and Partners in Policymaking; Perceptions of the biggest issues facing persons with I/DD and their families in Florida; Perceptions of biggest issues facing caregivers and family members of persons with I/DD in Florida; and Special Populations. Two in-person focus groups were facilitated with Partners in Policymaking advocates with 10 – 11 advocates in each group. Focus groups were audio recorded with permission, and the audio recordings were transcribed verbatim for analysis using a qualitative data software, MaxQDA. Transcripts were analyzed and themes were identified. Themes are topics that were mentioned multiple times by multiple focus group participants. In total, over 420 sections of text were coded into one or multiple themes and twenty (20) themes were identified.

While the focus group script was comprised of 11 questions, these questions can be divided into two (2) domains:

- Perceptions of the biggest issues facing persons with I/DD
- Perceptions of the biggest issues facing caregivers and family members of persons with I/DD in Florida

Each of the two thematic domains and the overarching themes for each are provided below.

Biggest Issues for Persons with I/DD

- Lack of funding for needed services
- Low funding for caregiver services leading to low quality service provision or inability to find a service provider
- Lack of local service providers for needed services
- Threats to iBudget Waiver, Including Waitlists
- Lack of knowledge and understanding of the I/DD system
- Unaware of rights
- Employment barriers
- Challenges in the public education system in accessing educational and therapy services
- Transition Assistance throughout Life Stages
- Aging of Persons with I/DD and Aging of their Family Members and Caregivers who Provide Support
- Restraint and seclusion a fear, especially for persons with dual diagnosis or maladaptive behaviors related to their I/DD

Biggest Issues of Families and Caregivers of Persons with I/DD

- Transportation
- Accessing quality services for their loved one
- Maintaining employment difficult due to various needs of person with I/DD not met by outside entity or provider, especially if not receiving iBudget
- Caregiver Fatigue and Burnout
- Financial burden related to unallowable costs, insurance coverage, added therapies and copays
- Knowledge of Services and How and When to Access
- Lack of social support due to inability to fully participate in society and social networks due to limitations of the person with I/DD, feeling ostracized by society at large
- Fear of mistreatment by police especially for those with maladaptive behaviors with I/DD
- Aging Family Members and Caregivers who Eventually Cannot Provide Support or Need More Caregiving Support (in Some Cases) than Their Loved Ones with I/DD

Focus Groups with Self-Advocates

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to develop a focus group script for use with self-advocates. Due to the rise of the coronavirus pandemic, the focus

group was facilitated virtually using Zoom. The focus group was facilitated by trained facilitators and seven self-advocates participated in the focus group. The purpose of the focus group was to: Identify the biggest issues for persons with I/DD and their families; Understand the impact of support received from caregivers/family; Understand their experiences with the I/DD system; and Identify needed services and improvements to the I/DD system. The focus group was audio recorded and were transcribed verbatim for analysis. Using MaxQDA, the transcripts were analyzed and themes were identified (themes are topics were mentioned multiple times by more than one focus group participant).

While the focus group script was comprised of eight (8) questions, these questions can be divided into four (4) main domains:

- Biggest issues self-advocates experience
- Impact of support received from caregivers/family
- Experiences with the I/DD System
- Recommendations for Improvements to I/DD system

Each of the four domains and the overarching themes for each are provided below.

Biggest Issues Self-Advocates Experience

- Transportation barriers
- Housing – lack of affordable, safe, accessible options
- Employment – difficult to work and keep state-sponsored benefits (Medicaid)
- Complicated and Challenging I/DD system:
 - Difficult to navigate the different systems
 - There are many providers and agencies involved, but there is a lack of interagency communication and
- Healthcare and personal care related issues:
 - Lack of Medicaid expansion
 - iBudget Waiver concerns including losing coverage or receiving less coverage
 - Being on the Waitlist with an unknown end date

Impact of Support Received from Caregivers/Family

- Support Received from Caregivers/Family
 - Help with physical needs including personal care, cooking and cleaning, shopping, etc.
 - Financial assistance

- Transportation
- Companionship
- Recreational opportunities
- Impact of Support Received
 - Ability to live in an apartment or family home instead of a facility
 - Access to services and employment via transportation provided
 - Personal safety
- Impact if Caregiver/Family Member Support Ended
 - Risk to safety and well-being
 - Lack of financial resources
 - Lack of emotional support and companionship
 - Lack of support navigating the I/DD system
 - Lack of transportation to employment and services
 - Caregivers/Family member support integral to the daily well-being of self-advocates. Without this support, self-advocates would need increased level of services from safety-net providers and the I/DD system. Loss of such supports would create a crisis situation for self-advocates.

Experiences with the I/DD System

- Difficult to navigate the disjointed system
- Lack of interagency communication within the system
- Self-advocates and advocates must call multiple places and people for help or answers and sometimes it is too complicated to find answers or resolutions
- Extremely difficult system to navigate for those who are new to I/DD or unfamiliar with the systems
- Medicaid is inadequate. Unable to get services that are needed. Difficult to find providers willing to accept low rates. Difficult to receive an increase in Medicaid Waiver services when needs change
- Without Medicaid Waiver, many people cannot access services. There is no statewide safety-net for them.

Recommendations for Improvements to the I/DD System

- Improve interagency communication
- Improve I/DD System's ability to respond to the changing needs of self-advocates
- Ensure all case managers are well-trained and familiar with available resources. Ensure continuity of care for self-advocates even if their case manager changes
- More education and training for care coordinators

- Increased pay for providers
- Expand Medicaid, remove people off the waitlist
- Evaluate of the system
- Peers helping peers navigate the system
- Ability for self-advocates to work without risk of losing benefits

Focus Groups with Aging Caregivers

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to develop a focus group script for use with aging caregivers. The focus group script can be found in the Appendix. Due to the rise of the coronavirus pandemic, the focus group was facilitated virtually using Zoom. The focus group was facilitated by trained facilitators and nine aging caregivers, defined as 60 years or older, participated in the focus group. The purpose of the focus group was to: Identify most important issues facing aging caregivers; Understand the daily and weekly role of caregivers; learn recommendations for improvements for the I/DD service system; and Understand aging caregivers' long-term plan for person with I/DD in their care. The focus group was audio recorded and were transcribed verbatim for analysis. Using MaxQDA, the transcripts were analyzed, and themes were identified. While the focus group script was comprised of eight (8) questions, these questions can be divided into three (3) main thematic need-based perceptions:

- Most Important Issues for Aging Caregivers
- Long-Term Care Plans
- Improvement Recommendations for the I/DD System

Each of the four domains and the overarching themes for each are provided below.

Most Important Issues for Aging Caregivers

- Lack of funding for needed services
- Low funding for provider services (personal care assistants, etc.) is leading to low quality service provision or inability to find a service provider willing to accept low rates
- Concerns related to the quality of service provided by caregivers (service providers)
- Lack of local service providers for needed services
- Threats to iBudget Waiver, Including Waitlists
- Lack of knowledge and understanding of the I/DD system, unable to know what services are available and how to access those services
- Caregiver burnout and continual stress related to being the primary parent/caregiver for a person with I/DD. This stress and burnout are not relieved by respite care or in-home assistance because

when there is a problem or an emergency, the primary parent/caregiver is needed. Caregivers are always “on”

- Lack of support for caregivers
- Concern related to personal health due to aging and lack of certainty related to who will take care of person with I/DD when aging caregiver is no longer able to serve in that capacity
- Without financial resources, it is difficult to prepare for long-term care of person with I/DD
- Concerned with possible abuse and neglect of person with I/DD, especially if that person is unable to communicate or has a dual diagnosis or maladaptive behaviors
- Concerned about personal safety and safety of person with I/DD due to maladaptive behaviors

Long-Term Care Plans

- Lack of long-term planning due to limited financial resources. Long-term care planning is expensive and requires financial resources. Many aging caregivers do not have access to those resources
 - Caregivers with long-term care plans worry those plans will not be followed, even though legal documents have been developed. Fear that the person with I/DD will no longer have an advocate working on his/her behalf when the aging caregiver passes away or is no longer able to serve as the primary caregiver.
- Difficult to find another person willing to be the primary caregiver for person with I/DD
 - Aging caregivers may expect a sibling/family member to care for the person with I/DD, but these wishes may not be communicated or agreed upon with the sibling/family member.
 - Difficult to understand the I/DD system, but there is not training available for sibling/family members to become prepared to be the primary caregiver once aging caregiver is no longer able to serve in the primary caregiver capacity.
- Aging caregivers need resources to develop long-term care plans for person with I/DD
- Need an option for aging caregivers and persons with I/DD to live together in the same facility or home with supports necessary to support persons with I/DD and persons without I/DD
- Need an option for persons with I/DD that provides a level of service less than an ICF, but more than a group home.

Improvement Recommendations for the I/DD System

- Funding needs to be secure. Planning cannot occur if there is a threat to the iBudget and Medicaid annually
- I/DD system is difficult to navigate and convoluted
- Better interagency coordination of services

- Increased funding is needed. Lack of funding means people are on the waitlist and unable to receive services
- A ranking system or way of scoring service providers is needed so caregivers and persons with I/DD can find quality providers
- Rigorous training for support care coordinators and providers is needed
- Must improve quality of services for persons with I/DD
- Expanded options for congregate living that accommodate needs of aging caregiver and their family member together

Surveys

An electronic survey was developed to poll persons with I/DD or their designated representative about service utilization, identification of unmet needs, reasons for the barriers experienced, and issues of importance to persons with I/DD. To be eligible to take the survey, individuals must have been 18 years of age or older, reside in Florida and be a self-advocate (i.e., person with a developmental disability) or their designated representative who is also 18 years of age or older. Individuals who did not meet the aforementioned criteria were not included in the data analysis. The survey included six (6) questions and five (5) demographic items. The Qualtrics® web-based surveying platform was used to deliver the survey and collect responses. The survey instrument was tested for readability. A Spanish language version was also available. Prior to deployment, the electronic versions of the survey were pre-tested for functionality and ease of use.

A related survey was developed to collect input specifically from the family members and caregivers of persons with I/DD. Survey items included: service utilization, unmet needs, barriers experienced by the self-advocate in their care, as well as questions on specific needs and challenges for the caregiver. The survey had seven (7) questions and five (5) demographic items on the self-advocate in their care and six (6) demographic items on the family member and caregiver. As with the self-advocate survey, the Qualtrics® web-based surveying platform delivered the survey and collected responses. A Spanish language version was also available. Both the English and Spanish versions were pre-tested for functionality and ease of use and were available in electronic formats only.

A convenience sampling approach (respondents are selected based on accessibility and willingness to participate) was utilized for collecting survey responses. Both the self-advocate and caregiver/family member survey went live on March 16, 2020 and remained available through April 20, 2020. Through professional contacts and FDDC's public relations firm, the survey links were shared and promoted throughout Florida. When the self-advocate survey closed, there had been 296 survey log-ins, which yielded 121 complete, eligible surveys for analysis.

The caregiver/family member survey garnered 748 log-ins that netted 553 complete, eligible surveys for analysis.

Key Findings from Self-Advocate Survey:

- Half of self-advocates who responded to the survey did not get the services they need; most frequently these included
 - Community support
 - Therapies
 - Employment and job training
 - Recreational opportunities
- Only 25 percent of self-advocates know what services they can get
- Only 20 percent of self-advocates said it was easy to get services
- Services self-advocates will need in the next 12 months include: community support services; medical, mental health, dental care, and wellness supports; transportation; recreation; and therapies

Key Findings from the Caregiver/Family Member Survey

- Most common reasons for unmet service needs include lack of providers and cost
- Top resource needs as caregiver include connections to other families of persons with I/DD, finding qualified providers, and respite care
- Critical issues as primary caregiver included fatigue/stress/burnout, worry about the future, and financial issues

Key Informant Interviews

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to identify key informants based on their insights and experiences into policy, funding, education, advocacy, the service delivery system and/or general perspectives regarding persons with I/DD in Florida.

The structured interview tool was comprised of thirteen (13) questions regarding the overall system of services for persons with I/DD; the biggest issues facing self-advocates and persons with I/DD in Florida; and discussion on the potential areas of priority and partnership for the FDDC. The structured interview tool, seen in the Appendix, was developed by WellFlorida Council in concert with the leadership of the FDDC.

The formal structured interview took between 1 and 1.5 hours to administer and was conducted by phone, ZOOM meeting, or Microsoft TEAMS meeting. Some key informants preferred to complete their

interview questions in writing, and then the “interview” consisted of WellFlorida following up with the key informant in order to glean more clarity or detail from the written responses. The purpose of the key informant interviews was neither to get direct quotes from individuals nor to obtain a statistically representative sample of perspectives. Rather, the purpose was to generate a list of key themes from a group of varying, highly-informed individuals, as a means to gain insight into the systems and needs of persons with I/DD and their families and caregivers.

While the structured interview tool was comprised of 13 questions, these questions can be comprised into three (3) main thematic domains:

- Biggest Issues for Persons with I/DD
- Biggest Issues of Families and Caregivers of Persons with I/DD; and
- Perspectives on Priority Areas of Focus for FDDC

Each key informant’s responses were thoroughly analyzed and themes (those ideas, concepts and perspectives most frequently mentioned) identified. Once identified, these overarching themes for each domain were catalogued for each of the three thematic domains. Each of the three thematic domains and the overarching themes for each is provided below.

Biggest Issues for Persons with I/DD

- Transportation
- Limited funding and Threats to iBudget Waiver, including Waitlists
- Service Drop-offs or Non-Uniform Services Availability throughout Life Stages
- Transition Assistance throughout Life Stages
- Aging of Persons with I/DD and Aging of their Family Members and Caregivers who Provide Support
 - Long-term care planning

Biggest Issues of Families and Caregivers of Persons with I/DD

- Transportation
- Housing (Tension between Maximizing Independence and Renewed Fears of Institutionalization Issues Evoked by New Housing Concepts)
- Caregiver Fatigue and Burnout
- Knowledge of Services and How and When to Access, Ability to Access Services with limited resources
- Aging Family Members and Caregivers Who Eventually Cannot Provide Support or Need More Caregiving Support (in Some Cases) than Their Loved Ones with I/DD

Perspectives on Priority Areas of Focus for FDDC

- Provision of comprehensive services throughout lifespan for persons with I/DD, including long-term care planning related to aging issues and their aging family members/caregivers
- Workforce development for persons providing services to the I/DD population and workforce development of the I/DD population to improve their employment opportunities
- Development of a service system that assists those with the most complex issues including those with dual diagnosis, maladaptive behaviors, etc.
- Influence the transition of the healthcare sector from “fee-for-service” to “value-based service”
- System performance assessment and ongoing evaluation to inform system redesign and funding decisions on an ongoing basis, including evidence-based system improvements

ANALYSIS OF STATE ISSUES AND CHALLENGES

Eligibility Criteria

In Florida, eligibility criteria are set by the federal, state, or local agency providing the service and supports. Among the factors considered in criteria setting are applicable federal and/or state statutes and regulations, funding source requirements and limits, professional best practices, and the scope, scale, and purpose of the services and supports. Documentation of a standard process for eligibility criteria review and update by Florida state agencies was not found. The Agency for Persons with Disabilities (APD) through its searchable web portal, known as “Florida Navigator” (Florida Agency for Persons with Disabilities, n.d.) lists the eligibility criteria for programs and services.

Issues related to eligibility surfaced in the public input portion of the assessment, in both the focus groups and self-advocate and caregiver/family member surveys. Focus group participants expressed consternation at the difficulty in accessing program information relevant to eligibility criteria, whether in print, electronic, telephonic, or in person. This was compounded for non-English speaking families. They relayed that getting assistance with forms and required documentation, having questions answered about one’s specific case, and determining where one’s application was in the approval process were time-consuming, frustrating, and often ended without resolution. Self-advocate survey respondents reported issues with eligibility related to unmet needs for therapies and transportation. Eligibility for education programs, services, and supports was reported as a barrier to those services by caregiver/family member survey respondents.

Barriers for Unserved and Underserved Persons

This assessment used multiple approaches to uncover and identify unserved and underserved populations in Florida. In the secondary data collection and analysis process, whenever possible

indicators that could be aggregated by age, gender, race and ethnicity were used. In addition, geographic sorting, by county and by FDDC service region, was conducted to identify differences by location and rural and urban settings. Poverty was another secondary data filter that was applied when feasible to spotlight any populations showing higher risks for negative outcomes and/or barriers to resources. The public input phase of the assessment process collected primary data through key informant interviews, surveys of self-advocates and their caregivers and family members and focus group discussions with several groups, including advocates from Partners in Policymaking (PIP), self-advocates, and the aging caregivers of persons with I/DD. As reported earlier, both surveys were available in Spanish and promoted and distributed statewide to Spanish-speaking groups. All three of the primary data collection methods incorporated questions to better understand: gaps in services, unmet needs of persons with I/DD and their families and caregivers, barriers to filling those needs, and which, if any, groups or populations experience greater needs and/or impediments in getting the services and supports they need. These secondary and primary data results were shared and reviewed with FDDC Council members at their regular meeting in May 2020. Council members examined assessment data and findings to identify where data pointed to common themes, converged on related issues and populations, and diverged or pointed to the need for further investigation. Using a facilitated consensus discussion process, Council members cataloged themes and issues of strategic importance and noted groups that merit focused interventions.

Three populations were identified as being unserved or underserved: aging caregivers for persons with I/DD, those with I/DD residing in rural areas of Florida and their families and caregivers, and persons with I/DD who have maladaptive behaviors and/or mental illness (dual diagnosis).

Aging Caregivers for Persons with I/DD

Secondary data show that more than 20 percent of Florida's population is 65 years of age or older (Demographics Table 5, Technical Appendix). In the super senior age group (those 80 years and older), since 1970 Florida's population has seen increases of 77.6 percent in the 80 to 84 years of age group. The 80 to 84 years of age group represented 2.5 percent of Florida's total population in 2018 and an increase of more than 300.0 percent in the 85 years and older age group to reach the 2018 proportion of the population at 2.6 percent (Florida Department of Health, 2020). From 2016-2018, the numbers of adults 18 years of age and older with I/DD have increased by about 2.0 percent each year (Demographics Table 11, Technical Appendix). The documented prevalence of I/DD in Florida is conservative and likely an underestimate. In Florida, at the highest percentage in the U.S., about 33.0 percent of those living with family caregivers live with aging caregivers aged 60 years and older (Perkins, 2019). In 2017 in Florida there were more than 350,000 caregiving families with only about six (6) percent receiving support from the state I/DD agency, that is, Florida's Agency for Persons with

Disabilities (Tanis, 2021). Public input data clearly pointed to aging caregivers as a special population. Focus groups articulated concerns for aging self-advocates as well as the family members who care for them. Almost 50.0 percent of caregiver/family survey respondents said among their highest concerns were fatigue, stress, and burnout, and worrying about the future, while more than one-third were concerned about financial issues. Another 20.0 percent cited managing other family responsibilities and their own physical health as top concerns. Resource needs for aging caregivers were also reported by these survey respondents. Almost 30.0 percent said they need respite care. About one-quarter need resources to meet the healthcare needs of the person in their care, local community-based services, and daily caregiving task assistance. Nearly 20.0 percent cited aging caregiver support as a top need (FDDC Caregiver/Family Survey, 2020).

Persons with I/DD Residing in Rural Areas

According to the latest U.S. Census estimates, Florida's 32 rural counties are home to about 1.1 million people. About 18,041 persons with I/DD live in rural Florida. Data show that Florida's rural population faces challenges with poverty, as a greater percentage live below the poverty level (16.4 percent) compared to Florida's urban counties (13.1 percent) (Demographics Table 8, Technical Appendix). Florida's rural population is older, with 21.3 percent of the population at 65 years of age or older compared to 19.6 percent in urban areas (Demographics Table 6, Technical Appendix). The 2020 County Health Rankings scored 16 of Florida's rural counties in the bottom quartile for the quality of health outcomes and health factors when compared and ranked with all Florida counties. None of Florida's rural counties ranked among the top ten in the annual rankings (Health Table 1, Technical Appendix). While these rankings do not specifically look at population disability factors, they provide an overarching look at the health and social environment and resources available to all persons. Public input pointed to challenges and barriers faced by persons with I/DD who live in rural areas. Focus group participants voiced concerns about the overall lack of access to services and supports linked to the limited providers and organizations that provide community-based services. Transportation was raised as a persistent issue, although noted to be a problem in both rural and urban areas. Information access, particularly in areas where Internet service is limited, was also raised as a barrier. Key Informant Interview participants equally expressed concerns for meeting the needs of rural Floridians in effective and cost-efficient ways.

Persons with I/DD Who Have a Dual Diagnosis (I/DD and Mental Illness and Severe or Maladaptive Behaviors)

According to the Agency for Persons with Disabilities, rates of Baker Acts for persons with I/DD is highest among persons who receive Behavior Scores 5 and 6 on the Questionnaire for Situational

Information (QSI). In calendar years 2015 – 2020, there were 66,781 APD consumers. Of those consumers, 22,227 had Behavior Scores 5 or 6 and 44,554 had Behavior Scores of 4 and below. In total, 2,870 APD consumers were Baker Acted. Even though persons with I/DD with Behavior Scores of 5 and 6 only represent 33 percent of APD consumers, they represent 80.55 percent of Baker Acts (Addendum Tables 1 and 2, Technical Appendix). In other words, persons with I/DD who receive high Behavior Scores on the QSI may be in need of additional services related to maladaptive behaviors. The Agency for Persons with Disabilities does not serve all Florida residents with I/DD. It is estimated that there are approximately 336,529 people living with I/DD in Florida, indicating the number of persons with I/DD who were Baker Acted from 2015 – 2020 could be much higher (Addendum Table 2, Technical Appendix).

Concerns for persons with I/DD and a dual diagnosis was discussed by three focus groups: Partners in Policymaking (two groups) and the aging caregivers focus group. According to focus group participants, persons with I/DD and maladaptive behaviors or mental illness (dual diagnosis), may exhibit disruptive behaviors that may be misunderstood by law enforcement leading to restraint and seclusion or restrictive settings. Furthermore, focus group participants discussed the need for additional services for this I/DD population expressing concerns that managing significant behavioral challenges requires many services and supports throughout the lifespan.

Availability of Assistive Technology

Assistive technology services and devices are available to Floridians through several means. The Florida Alliance for Assistive Services and Technology, Inc. (FAAST) is a nonprofit organization funded through the Assistive Technology Act of 2004 and the Florida general revenue funds under Florida Statute 413.407. The Florida Department of Education, Division of Vocational Rehabilitation is FAAST's sponsor. FAAST's mission focuses on improving the quality of life for all Floridians with disabilities through increasing access to assistive services and technology. Core services include assistive technology (AT) device loan programs, AT device refurbishing and recycling programs, AT device exchange, skills development and transition trainings, AT device demonstrations, AT information and technical assistance, and the New Horizon Loan Program.

There are six regional demonstration centers (RDC) that offer FAAST services locally. Sites include the Atlantic RDC at the University of Central Florida in Orlando, Central Florida RDC at Tampa General Hospital Rehabilitation Center in Tampa, Gulf Coast RDC at the Center for Independent Living Disability Resource Center in Pensacola, Northeast RDC at Hope Haven Children's Clinic in Jacksonville, Northwest RDC at The Family Café in Tallahassee, and the South Florida RDC at the University of Miami Mailman Center in Miami. In 2019, 97.5 percent of FAAST customers rated their satisfaction with services as satisfied or highly satisfied. During that same time period, about 470 devices were

exchanged, netting customers combined savings of nearly \$70,000. Device refurbishments numbered nearly 1,300, resulting in combined net savings for consumers of more than \$250,000. FFAST's 1,087 demonstrations reached more than 3,300 individuals, and 13,334 participants benefited from trainings. FFAST trainings were concentrated in Florida's metropolitan areas, where 78.0 percent of trainings took place (Assistive Technology Tables 1-6, Technical Appendix).

As part of their mission to "help people with disabilities find and maintain employment and enhance their independence," the Florida Department of Education (DOE) Division of Vocational Rehabilitation (VR) provides AT for community and independent living, workplaces, and education settings. In 2019, VR invested 9.0 percent of its client services expenditures on AT (Florida Department of Education, Division of Vocational Rehabilitation, 2019).

Florida DOE Bureau of Exceptional Education and Student Services (BEES) assures that students with disabilities have access to assistive technology devices and accompanying services (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2013). Florida Diagnostic and Learning Resources System (FDLRS), offers services for the appropriate use of numerous technologies for students, teachers, professional staff and parents. Through FDLRS, students and teachers have access to a statewide assistive technology loan library.

Persons with I/DD may have access to AT services through Medicaid and the iBudget Florida Home and Community-Based Services Waiver. The AT options that may be available include ambulatory aids, vehicle adaptation, wheelchairs, carriers, and lifts. Home technologies could include adaptive switches for equipment operation, doors locks and openers, and communication devices.

Waiting Lists

A major issue for the iBudget is the lack of fiscal support it receives from the Florida legislature, causing many individuals to be placed on a waitlist until they are able to receive services. Approximately 60 percent of persons receive services, while 40 percent are on the waitlist (Agency for Persons with Disabilities, 2020). As of February 2020, the waitlist has 22,865 persons on it, where the total of all individuals waiting for services are separated into categories to assess the highest need clients first (Informal and Formal Services and Supports 23, Technical Appendix). Individuals deemed to be in "crisis" receive priority.

Compared to the United States, Florida has the highest percentage of persons on a waiting list living with aging caregivers. An aging caregiver is defined as an individual over the age of 60 who is caring for their adult child. Due to this, there are impacts to the overall family unit, as caregivers must wait until they reach age 70 for their aging, adult children to receive iBudget services.

Florida ranks 49th out of 50 states in “fiscal effort” or I/DD funding. As a comparison, New York, which is ranked 1st out of 50 states, spends \$9.06 per \$1,000 of personal income; Florida spends \$1.99 per \$1,000 of personal income (Tanis, 2021). Additionally, Florida’s overall fiscal effort has decreased by approximately 10 percent since 2007 (Perkins, 2019).

Analysis of Adequacy of Current Resources and Projected Availability

At the time of this assessment, Florida, the United States, and the world are in the midst of the response to a global coronavirus pandemic and in various stages of recovery in citizens’ health, healthcare, and social system resource availability, as well as economic impact. In Florida, the current unemployment rate in April 2020 rose to nearly 13.0 percent from the February rate of 2.3 percent. March sales tax revenues were more than \$770 million less than planned with April losses expected to be larger. Medicaid enrollments are surging and predictions of up to one billion dollars in additional Medicaid spending are reported (Sexton, C. News Service of Florida, 2020). Florida’s Fiscal Year 2020-2021 budget of \$92.2 Billion, was signed into law on June 29, 2020 (Governor Ron DeSantis Staff, 2020). The analysis that follows uses fiscal projections made before the pandemic. Many of these projections will likely change; however, for planning purposes, the following information provides a history and baseline for projections.

According to Florida’s three-year fiscal outlook for fiscal years 2020-2021 through 2022-2023, prepared jointly by The Senate Committee on Appropriations, The House Appropriations Committee, and The Legislative Office of Economic and Demographic Research, Florida will need an additional \$6.18 billion in general revenue over those three years to cover services in ten policy areas. As shown in the table below, general revenue needs in prekindergarten through 12 education, as well as human services, are predicted to increase to 18.5 percent and 22.9 percent, respectively, of overall general revenue spending. Many of the services vital to persons with I/DD are financed through these policy areas. Specific to the Agency for Persons with Disabilities, a projected increase of \$22.4 million in general revenue will be needed each for each of these three fiscal years, in an effort to finance the following: a reduction of the waitlist for services for persons with I/DD, administrative service to manage growth in the iBudget Florida Waiver services, supported employment and internship programs, and rate increases for Medicaid Waiver providers. As of February 2020, more than 22,000 individuals are on the iBudget Waitlist or Waiver services.

Florida’s total spending for intellectual and development disability spending has risen. The comparative proportions of non-Medicaid spending and Home and Community-based Services (HCBS) Waiver, Intermediate Care Facility for Persons with Intellectual Disabilities and related Medicaid spending have remained relatively static since 2001 when those proportions reached 20 percent and 80 percent,

respectively (Tanis, 2021). The sources for public spending for intellectual and developmental disability services in Florida are 35 percent state funded and 65 percent federally funded. Trends in fiscal efforts for community and institutional spending for intellectual and developmental disability services show a divergence since the year 2000 with spending on institutional services falling and community service spending increasing exponentially based on dollars spent per \$1,000 personal income (State of the States in Intellectual Disabilities, Florida Profile, 2020).

According to the Florida Department of Education's State Report Card, total costs per student for the 2019-2020 school year were \$8,859 (Florida Department of Education, 2020). Sources of funding for school districts in 2018-2019 were 39.9 percent from state sources, about 48.8 percent from local sources, and 11.3 percent from federal sources. Program cost factors are used to assure an equitable distribution of funds in relation to relative costs per student. Basic program cost factor weights for Kindergarten and grades 1, 2 and 3 (cost factor weight 1.124) are the same as for programs for exceptional student education, and this holds true for basic programs and grades 4, 5, 6, 7 and 8 with exceptional student education services (cost factor weight 1.000) as well as grades 9, 10, 11 and 12 with exceptional student education services (cost factor weight 1.012). Program for exceptional student education at support levels 4 (cost factor weight 3.644) and 5 (5.462) reflect a cost investment for these students (Florida Department of Education, n.d.). Florida Department of Education's federal fiscal year 2021 annual state application for IDEA Part B funding shows state fiscal year 2019 state financial support for special education and related services for students with disabilities at 1.002 Billion dollars or \$2,471.43 per student receiving these services. Small increases were reported for the 2020 state fiscal year at 1.073 Billion dollars and \$2,552.38 per student (Florida Department of Education, 2021). The Special Education Expenditure Project report found that nationally per pupil education expenditures vary by disability category and that spending per student is about 1.9 times higher for those who receive special education services (Center for Special Education Finance, 2003).

According to the *National Report on Employment Services and Outcomes*, (Winsor, 2019), in Florida about 23.5 percent of working-age persons with a cognitive disability are employed, compared to 33.3 percent of those with any disability, and 73.2 percent of persons with no disability. Employment outcomes for working-age Floridians show that the percentage of persons with no disability living below the poverty line in 2017 was 12.0 percent, 25.4 percent for persons with any disability, and highest for persons with a cognitive disability at 28.3 percent. Vocational Rehabilitation reports in 2017 that the average number of days from eligibility to case closure into employment for persons with I/DD was 689 days with 29.2 percent of closures for persons with I/DD resulting in employment (Winsor, 2019). The percent of supported employment for persons with I/DD is as low as 12 percent with the numbers of participants down noticeably (Tanis, 2021).

Data from the National Core Indicators (NCI) survey of persons with I/DD in Florida point to continuing challenges with transportation barriers not only for accessing essential services but also in connection with staying in contact with friends and socializing. For example, 47 percent of NCI survey respondents said lack of transportation was a barrier to seeing friends as compared to 38 percent nationally. Lack of transportation was the biggest barrier, outscoring money, time, support staff, and rules or regulations. Only 20 percent of persons with I/DD who responded to the NCI survey reported having attended a self-advocacy meeting or event and about 36 percent report having voted in a local or national election (National Core Indicators, 2019).

Florida's fiscal resources to support persons with I/DD in finding services and supports have historically been among the lowest in the nation with a decrease in fiscal effort of about 10 percent since 2007 (Perkins, 2019). Population growth compounds funding inadequacy as Florida's population expands in numbers and diversity. 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.

Analysis of Adequacy of Healthcare and Other Services, Supports and Assistance for Persons with Intellectual and Developmental Disabilities who are in Facilities

Over the past 50 years, shifts in scientific research, public awareness, policy and legislative changes and strong self-advocacy from persons with I/DD and their families spurred institutional reform and significant growth in community living for persons with I/DD. Nationally, about 75 percent of adults with I/DD live with parents or other family members, with the majority not receiving any formal services or supports (Friedman, 2019). According to Tanis et al in *The State of the States in Intellectual and Developmental Disabilities* (Tanis, 2021), in 2017 in Florida more than 30,000 persons with I/DD resided in nursing facilities, state institutions, private ICF/IDs, other residential facilities and supported living facilities.

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) deliver rehabilitative and health services to persons with I/DD in protected, residential settings. Need of and receipt of active treatment, which consists of ongoing, consistent, specialized and generic training, treatment, and health services, is a requirement for Medicaid coverage for ICF/IID care. Eligibility for Florida Medicaid recipients requiring ICF/IID services is determined by Florida's Agency for Persons with Disabilities (APD). ICF/IIDs are designed to provide the highest levels of support and interventions for persons with I/DD paid for using federal dollars. According to the Florida Association of Rehabilitation Facilities (Florida ARF), there are 87 ICF/IIDs in Florida with a total of 2,071 licensed beds. The

occupancy rate for ICF/IDs is approximately 95 percent. In Florida the number of ICF/IDs beds is currently frozen by a licensure moratorium. Florida's ICF/IDs include 38 six- (6) bed homes, 27 cluster facilities, six (6) 64-bed campuses, and 16 other facilities with variations of these models. Six-bed homes are located in residential areas with operations similar to group homes where residents can be involved in community activities. Clusters are comprised of three (3) homes located close together but operating as separate living units. Four (4) semi-private rooms make up each home. Clusters tend to specialize in serving medically fragile persons with I/DD and provide extensive medical and rehabilitative services. Four (4) separate living units each with eight (8) semi-private rooms make up the 64-bed campus model where residents can be active in day programs and community activities (Florida Association of Rehabilitative Facilities, n.d.).

The Florida APD operates two state-run ICF/IDs that together house and serve more than 700 residents. Tacachale Center in Gainesville is home to about 200 persons with I/DD while the Sunland Centers in Marianna served more than 500 individuals. Both centers strive to ensure all residents receive quality care and treatments along with training to support and strengthen self-determination. Community involvement and community living are fostered along with individualized goal setting towards self-determination and independence (Florida Agency for Persons with Disabilities, n.d.).

In summary, Florida's population growth, an aging population of both persons with I/DD and their caregivers, rising health and related service costs, workforce challenges, and competing funding priorities contribute to escalating concerns about the adequacy and sustainability of the health care and other services and supports for persons with I/DD in facilities. Increases in total funding, as seen in recent years, are insufficient to close existing gaps while accommodating rising numbers of persons with I/DD in need of the specialized care they deserve that is provided in these facilities.

Analysis of Home and Community-Based Waiver Services (HCBS)

In Florida, federal Medicaid intellectual and developmental disability service spending for the HCBS Waiver took a precipitous turn upward around the year 2000, while spending by public and private revenue sources were nearly level with a slight downturn in 2017. In fiscal year 2017 in Florida, of the 1.53 billion dollars spent by federal and state Medicaid on intellectual and developmental disability services, about 58 percent was in the Medicaid HCBS category, and 22 percent in Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities, followed by 16 percent in other federal spending and four (4) percent in other state Medicaid spending (Tanis, 2021). HCBS Waiver costs by fiscal year per participant in Florida were most recently reported at \$32,700.

Data from the National Residential Information Systems Project (RISP) indicated that since 2005 through 2016, the vast majority of persons with I/DD who lived in individualized settings, resided in a

family home. As Florida's population grows the prevalence of I/DD will increase, placing increasing demand on home and community-based supports and services. Florida's numbers of individuals who live in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) remained relatively constant from 1982 to 2017, as seen in the RISP data below. The waitlist for iBudget Florida waivers hovers above 20,000 individuals, while the Agency for Persons with Disabilities (APD) caseload, including persons living in the home of a family while on the waitlist, increased incrementally to more than 58,000 persons (University of Minnesota, Residential Information Systems Project (RISP), Research and Training Center on Community Living, Institute on Community Integration, 2017)

Florida Agency for Persons with Disabilities (APD) had a waiting list of 22,865 persons in February 2020. Florida has the highest percentage of persons on a waiting list living with aging caregivers in the United States. An individual over the age of 60 who is caring for their adult child is deemed an aging caregiver. The figure below displays the trends in numbers of long-term support and services recipients; Medicaid recipients; and those on the waiting list.

Many data sets underscore the need for investments in HBCS in Florida are shown in the figures that follow. Seventy-five (75) percent of persons with I/DD live with a family caregiver. Only one-third (33 percent) of persons with I/DD live with family caregivers under the age 41 and almost as many (31 percent) live with aging caregivers, that is, a caregiver aged 60 and above. In 2017 in Florida there were more than 350,000 caregiving families with only about six (6) percent receiving support from the state I/DD agency, that is, Florida's APD.

Persons with I/DD, their family and caregivers face challenges in many regards, few greater than in the area of Florida's adequacy to deliver quality, timely and sufficient HBCS. Shifting demographics make the issue more complex and more urgent for Florida to address. APD, Florida's state agency responsible for administering HBCS waiver and individual budgeting (iBudget) has led these efforts since 2013. The Florida Legislature continues to focus on the waiver budget and APD with eye towards both efficiency and meeting the health care needs of persons with I/DD in an environment of rising costs, challenging provider reimbursement rates, and workforce capacity and supply. Bold leadership and creative system changes are in order to thwart the further erosion of health, safety, and quality of life for persons with I/DD and those who care for them.

IDENTIFICATION OF STRATEGIC PRIORITIES AND GOALS

Florida Developmental Disabilities Council Members approached the selection of strategic priorities for the next five years using a methodical, data-driven, and collaborative process. The first step included the sharing, review and discussion of the secondary and primary data from the comprehensive review and analysis. On May 14, 2020, WellFlorida Council presented highlights from the assessment that

included state information on developmental disabilities in Florida and a portrait of health care, employment, informal and formal services and supports, interagency initiatives, education and early intervention, quality assurance, housing, transportation, childcare and recreation. Findings and themes from the public input phase of the assessment were shared. These included highlights from a focus group of self-advocate leaders and 16 key informant interviews along with summary findings from the self-advocate survey and caregiver/family member survey. The presentation slides, a recording of the presentation and supporting data compendium were made available to Council Members for their further study and review. Based on these findings, Council Members requested additional in-depth information from two emerging priority groups; that is, self-advocates and aging caregivers of persons with I/DD. Two focus groups were convened In June 2020 as described earlier in this report and the information gained was used to strategize goal, objective and action planning. A week in advance of the August FDDC Council meeting, a virtual “drop in” session was held in which members could ask any remaining questions about the comprehensive review and analysis, secondary or primary data, or findings presented to date.

The FDDC Council Members discussed and approved the criteria proposed by WellFlorida Council.

Typical criteria used in strategic planning include:

- Data-informed
- Importance
- Impact
- Urgency
- Feasibility
- Resource availability

Presented below are the intersecting themes or major needs and issues for persons with I/DD and their families and caregivers. These intersecting themes were also considered in the identification and prioritization of potential strategic issues. For ease of understanding common themes and root causes, the key issues are grouped below into categories including social determinants of health, health status and health behaviors, health resources, and community infrastructure. Many of the key issues emerged as concerns across the intersecting theme areas shown below; however, each issue is only listed once. It is important to note that going forward in their discussions, Council Members opted to use the term dual diagnosis to describe the areas of concern related to severe behavioral issues, maladaptive behaviors, and co-occurring diagnoses of I/DD and mental health issues.

- Access to Community Services and Supports
 - Availability and access to services, supports, providers

- Meeting basic housing and transportation needs
- Recreational opportunities
- Social acceptance and supports
- iBudget Preservation
 - Managed care and service delivery systems including Medicaid
 - Wait list
- System Complexity and Accessibility
 - Funding and fiscal accountability of agencies
 - Elimination of mistreatment, bias and discrimination in systems and practices
 - Service quality, uniformity and continuity
- Aging Caregivers and Aging Self-Advocates
 - Caregiver fatigue and burnout
 - Financial burdens for self-advocates and families
 - Rights of self-advocates and caregivers
- Education, Job Training and Employment
 - Post-secondary transition
- Disparity Population
 - Persons with dual diagnosis of I/DD and mental health issue and/or exhibiting maladaptive behaviors or severe behavioral issues
- Emerging Issues
 - Systems change
 - Flexibility to address emergencies and changing conditions

At the virtual August 20, 2020 FDDC meeting, the comprehensive review and analysis findings were discussed and organized into the themes presented above. Pandemic conditions required that the prioritization process be conducted virtually. This was accomplished via electronic survey whereby Council Members scored the 26 agreed upon key issues and themes. These were ranked using the criteria shown in the table above. Each key issue was rated for magnitude including importance and urgency and secondly, confidence to successfully address the issue considering its potential impact, feasibility, and resource availability. Council Members also ranked their picks for the top three (3) priority issues. Using a weighted scoring rubric, the ranked list of potential priority issues was generated.

At the September 10, 2020 FDDC meeting, survey results were presented and discussed. A facilitated consensus discussion afforded Council Members to ask questions, review data, challenge thinking, advocate for issues, consolidate, remove duplicative topics, and organize themes into issue areas with commonalities such as shared root causes or potential shared strategies for addressing. Council Members refined issue labels to more concisely group them. The priority issue areas below moved forward for consideration in the five year state plan.

- Access to Services
 - Community support services (services that keep persons with I/DD in the home and community)
 - Meeting basic housing and transportation needs
 - System complexity and support for agencies that provide services including the professionals who provide care and services
 - Service quality, uniformity, continuity and assurance of freedom from bias and discrimination
 - Wait list
- iBudget Preservation
 - Managed care and service delivery systems including Medicaid
 - Fiscal accountability of agencies
- Aging Caregivers
 - Aging self-advocates
 - Caregiver fatigue and burnout
 - Financial planning and financial burden relief for self-advocates, families, and caregivers
- Emerging Issues
 - Systems change
 - Flexibility to address emergencies and changing conditions
- Disparity Population of Persons with Dual Diagnosis of I/DD and Mental Health Issue
 - Resources and services for persons with severe behavioral challenges and/or maladaptive behaviors

In order to develop the five year state plan, a small workgroup including Council staff and Council members met to draft the five year state plan over the course of several months. The draft five year state plan was presented to the full Council on January 22nd 2021. The Council voted to approve the draft plan and move forward with the required 45 day public input time period. WellFlorida Council

developed and FDDC staff approved a public input survey that was available in four versions: English standard, English Easy Read, Spanish standard, Spanish Easy Read. At the conclusion of the 45 day public input time period, 141 completed surveys were analyzed. The proposed five year state plan received strong support from survey respondents. Based on the public input received, the five year state plan was adopted as drafted and no changes were recommended. The following chart includes the Priority Areas and Goals as adopted.

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.
Priority Area: Sustain Medicaid Home and Community-Based (iBudget) Services
Goal 2: Individuals with intellectual and developmental disabilities (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.
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.
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.
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.

Introduction

FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL (FDDC) COMPREHENSIVE REVIEW AND ANALYSIS PROCESS

The FDDC engaged the services of WellFlorida Council to conduct a comprehensive assessment, review, and analysis process. WellFlorida Council is the statutorily designated (F.S. 408.033) local health council that serves 16 north central Florida counties. The mission of WellFlorida Council is to forge partnerships in planning, research, and service that build healthier communities. WellFlorida achieves this mission by providing communities the insights, tools, and services necessary to identify their most pressing issues and to design and implement approaches to addressing those issues. WellFlorida Council also is a lead partner in the Florida Association of Health Planning Agencies. The Association's mission is to support state, regional, and local assessment via data-driven, collaborative planning that seeks to enhance and improve health resources, systems, and outcomes for all Floridians.

This comprehensive assessment, review, and analysis effort follows the guidance of the NACDD (National Association of Councils on Developmental Disabilities, Information and Technical Assistance Center for Councils on Developmental Disabilities, 2020) and incorporates tenets of a nationally recognized model and best practice for collaborative community health assessment processes called Mobilizing for Action through Planning and Partnerships (MAPP). The MAPP tool, developed by the National Association of County and City Health Officials (NACCHO), in cooperation with the Centers for Disease Control and Prevention (CDC), helps assure factors related to health equity and health disparities are considered, along with maintaining a focus on identifying actionable strategic priorities to improve the quality of life for persons with I/DD and their families (National Association of County and City Health Officials, n.d.). The comprehensive assessment and strategic planning process started in October 2019 and concludes with this report in June 2021.

METHODOLOGY

Generally, the health and well-being of a group is measured by the physical, mental, environmental, and social well-being of its members. Due to the complex determinants of health and quality of life, assessment and review is driven by quantitative and qualitative data collection and analysis from both primary and secondary data sources. In order to make the data and analysis most meaningful to the end user, this report has been separated into multiple components as follows:

- State Information
 - Demographic and Socioeconomic Factors
 - State Disability Characteristics

- Portrait of the State
 - Health and Healthcare
 - Employment
 - Informal and Formal Services and Supports
 - Interagency Initiatives
 - Quality Assurance
 - Education and Early Intervention
 - Housing
 - Transportation
 - Childcare
 - Recreation
- Public Input
 - Focus Groups
 - Surveys
 - Key Informant Interviews
- Analysis of State Issues and Challenges
 - Eligibility Criteria for Services
 - Barriers for Unserved/Underserved
 - Availability of Assistive Technology
 - Waiting Lists
 - Analysis of Adequacy of Current Resources and Projected Availability
 - Analysis of Adequacy of Healthcare and other Services, Supports and Assistance for Persons with I/DD who are in Facilities
 - Analysis of Adequacy of Home and Community-based Waiver Services
- Identification of Strategic Priorities and Goals
 - Process and Criteria for Selection
 - Intersecting Themes
- Strategic Priority Issue Areas
- FDDC Five Year State Plan (2022-2026)
- References
- Appendix
 - Council Members
 - Focus Group Script
 - Key Informant Interview Script
 - Survey Materials

This comprehensive review represents a process of systematically gathering and analyzing data relevant to the well-being and quality of life of persons with I/DD and their families and caregivers. Such data will help to identify unmet and emerging needs, gaps in services, state and regional challenges, as well as areas of positive gains. Findings from this process will be used to explore and understand the needs of persons with I/DD as a whole in Florida, as well as for specific demographic and geographic subsets whenever possible.

Many of the data tables in the technical report contain standardized rates for the purpose of comparing data for Florida as a whole and regional data when available with national data. It is advisable to interpret these rates with caution when incidence rates are low (i.e., the number of new cases is small). Small variations from year to year can result in substantial shifts in the standardized rates. The data presented in this summary include references to specific tables in the *Technical Appendix* so that users can refer to the numbers and the rates in context.

State Information

This section presents the key data sets from the *Technical Appendix* to describe the population of Florida as a whole and the Florida population of persons with I/DD in particular. Indicators in this section describe racial and ethnic diversity, as well as socioeconomics, poverty status, and other characteristics of the population of persons with I/DD. The assessment data were prepared by WellFlorida Council, Inc., using a diverse array of sources including the U.S. Census Bureau, U.S. Department of Labor, Centers for Disease Control and Prevention, Florida Department of Health Office of Vital Statistics, and a variety of health data sites from respected institutions across the United States and Florida.

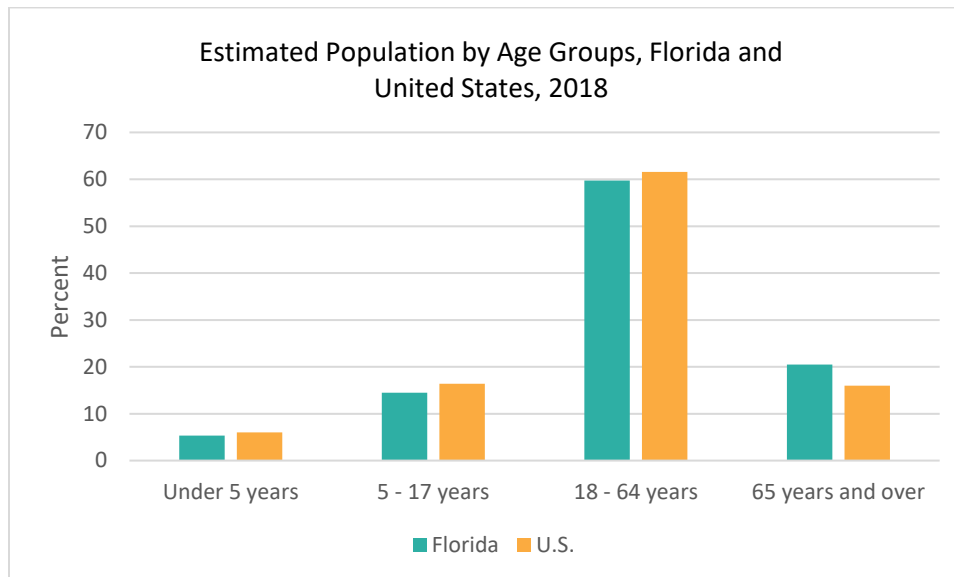
DEMOGRAPHICS AND SOCIOECONOMICS

As population dynamics change over time, so do the healthcare, social service, education, and economic needs of residents. It is important to periodically review key demographic and socioeconomic indicators to understand current issues and anticipate future needs. The *Technical Appendix* includes data on current population numbers and distribution by age, gender, and racial group by geographic region. It also provides statistics on education, income, and poverty status. It is important to note that these indicators can significantly affect populations through a variety of mechanisms including material deprivation, psychosocial stress, barriers to healthcare access, and the distribution of various specific risk factors for acute and/or chronic illness. Noted below are some of the findings from the state profile.

POPULATION

The U.S. Census Bureau's American Community Survey (ACS) Single-Year Estimates for 2018 reports Florida's total population at 21,299,325, with 48.8 percent males and 51.2 percent females. Compared to the U.S. as a whole, Florida has a higher percentage of persons 65 years and older (Demographics Tables 1, 2, 3, Technical Appendix). Florida has an overall older population, with 20.5 percent of the population aged 65 years and older compared to 16.0 percent for the U.S. As seen in the figure below, the percentage of Florida's population in the "under 5 years," "5 to 17 years," and "18 to 64 years" categories fall below the national percentage (Table Demographics 5, Technical Appendix).

TABLE 1. ESTIMATED POPULATION BY AGE GROUPS, FLORIDA AND UNITED STATES, 2018

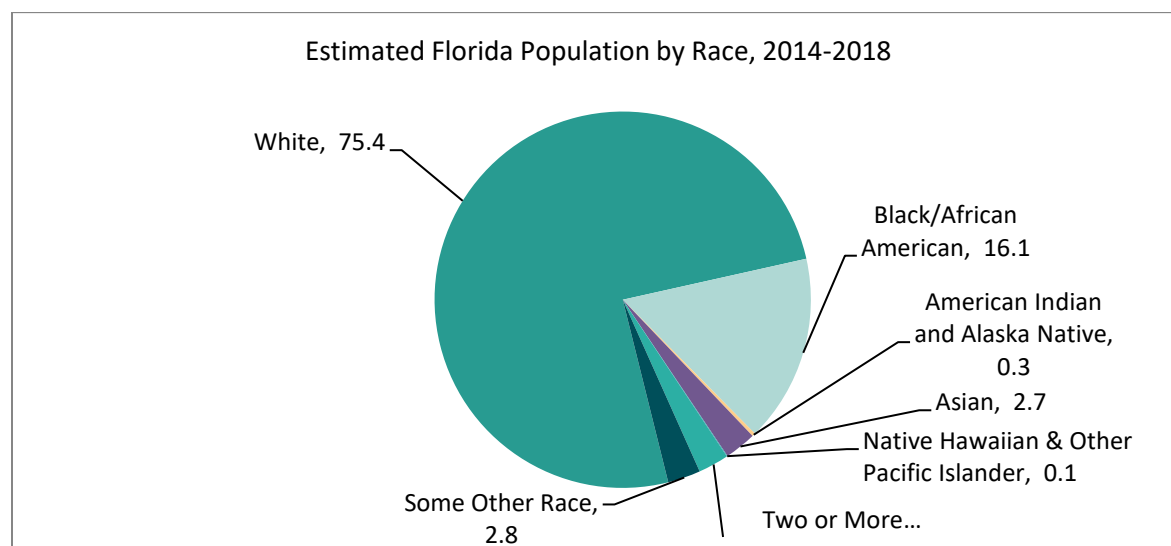


Source: 2020 Technical Appendix, Demographics Table 5, 2020.

RACIAL AND ETHNIC DIVERSITY

The racial and ethnic diversity of Florida's population is shown in the charts below. In 2018, 74.6 percent of Florida's population was White, 16.0 percent was Black or African American, and 26.1 percent identified as Hispanic compared to 72.2, 12.7, and 18.3 percent, respectively, for the U.S. as a whole (Demographics Table 1, Technical Appendix).

FIGURE 1. ESTIMATED POPULATION BY RACE, FLORIDA, 2014-2018

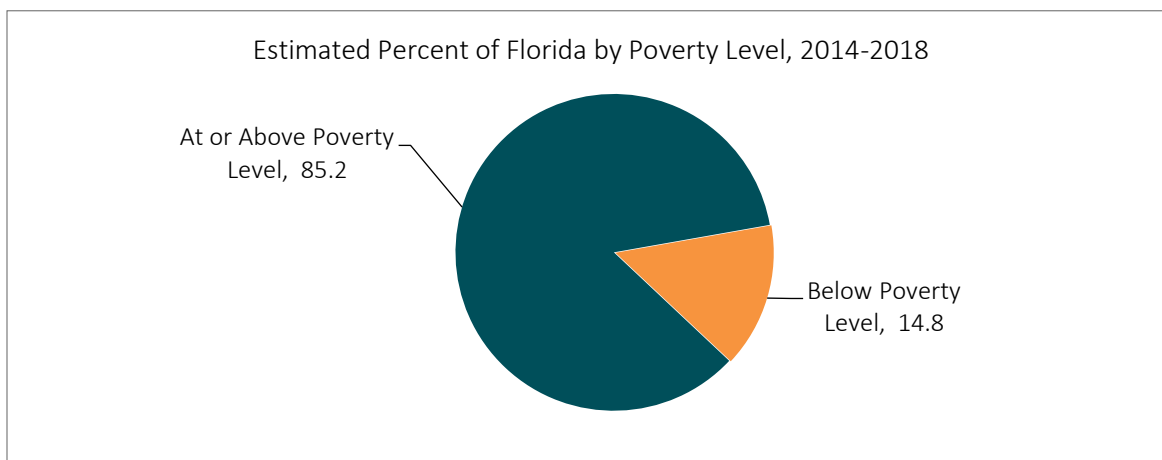


Source: 2020 Technical Appendix, Demographics Table 1, 2020.

POVERTY

In Florida for 2014-2018, it is estimated that 14.8 percent of the population lived below the Federal Poverty Level (FPL), which is slightly higher than the rate for the U.S. as a whole, at 14.1 percent. There were differences in poverty rates by region, rural, and urban designations, amongst the population aged 16 years and older. About 16.4 percent of residents over the age of 16, in the 32 Florida rural counties, lived below the FPL, compared to 13.1 percent of residents in the remaining 35 urban Florida counties (Demographics Table 8, Technical Appendix). By gender, in Florida, higher percentages of males (13.7 percent) and females (15.8 percent) lived below the FPL when compared to national percentages (12.8 and 15.3 percent, respectively). In Florida when examined by race, higher percentages of Whites (12.7 percent), Asians (12.5 percent), and Native Hawaiian and other Pacific Islanders (23.4 percent) lived below the FPL than national rates (11.6, 11.5, and 18.3 percent, respectively). The percentage of those of Hispanic or Latino origin living below the FPL in Florida was lower than the national figure (18.9 percent compared to 21.0 percent, respectively). (Demographics Table 9, Technical Appendix).

FIGURE 2. ESTIMATED PERCENT BY POVERTY LEVEL, FLORIDA 2014-2018



Source: 2020 Technical Appendix, Demographics Table 7, 2020.

STATE DISABILITY CHARACTERISTICS

PREVALENCE OF DEVELOPMENTAL DISABILITIES

In Florida in 2018, there were an estimated 336,529 persons with I/DD. This calculation was based on the prevalence rate of 1.58 percent of the general population as reported by Larson and colleagues (Larson & Lakin, 2001). The general population used in these calculations was based on the U.S. Census Bureau ACS Single-Year Population Estimates for 2016-2018 (Demographics Table 10, Technical Appendix). This overall prevalence rate is recommended for use in the development of five year plans by the NACDD (National Association of Councils on Developmental Disabilities, Information and Technical Assistance Center for Councils on Developmental Disabilities, 2020) and is used in Florida's

comprehensive assessment and analysis. Based on this prevalence rate, the number of persons with I/DD has increased as Florida's population grows.

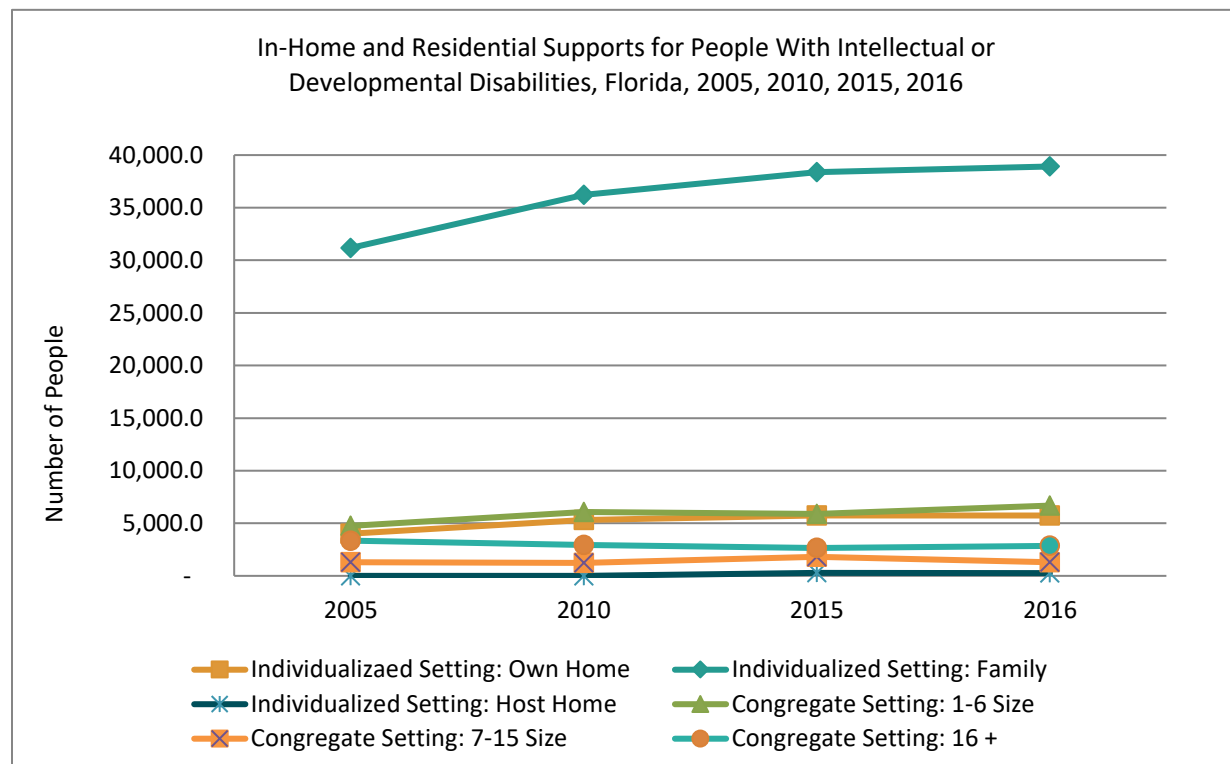
For comparison, the methodologies used by Zablotsky and colleagues were examined. To calculate the estimated prevalence of I/DD by age groups, Zablotsky recommends applying 6.99 percent to the noninstitutionalized population from birth to 17 years of age (Zablotsky, 2017) and Larson applies 0.79 percent to the noninstitutionalized population ages 18 years and older (Larson & Lakin, 2001). Again, using the U.S. Census Bureau ACS Single-Year Population Estimates for 2016-2018, as well as the aforementioned rates, the prevalence of I/DD among Florida's children, is calculated at 295,528 (from birth through 17 years of age in 2018) and 134,864 for adults (18 years of age and older in 2018). (Demographics Table 11, Technical Appendix).

Recent national studies have found increases in the diagnosis of developmental disabilities among children in the U.S. (National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 2019). From 2009-2011 to 2015-2017, the percent of children aged 3-17 years diagnosed with developmental disabilities rose by 7.4 percent overall, from 16.2 to 17.8 percent. There were marked increases by specific diagnoses, such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD). The diagnosis of ADHD among children for that same period rose by 11.8 percent, while ASD diagnoses grew by 127.3 percent and intellectual disabilities by 33.3 percent (Demographics Table 14, Technical Appendix).

RESIDENTIAL SETTINGS

Data from the National Residential Information Systems Project tracks in-home and residential supports for persons with intellectual or developmental disabilities (University of Minnesota, Residential Information Systems Project (RISP), Research and Training Center on Community Living, Institute on Community Integration, 2017). In Florida, from 2005 to 2016, the vast majority of persons with intellectual or developmental disabilities who lived in individualized settings, resided in a family home. In 2016, 86.6 percent of those in individualized settings lived in a family home. In 2016, about 61.7 percent of persons with intellectual or developmental disabilities who resided in congregate settings, lived in sites that accommodated one to six persons. More than one-quarter (about 26.4 percent) were reported to have lived in congregate sites with 16 or more persons for that same year (Demographics Table 15, Technical Appendix).

FIGURE 3. IN-HOME AND RESIDENTIAL SUPPORTS FOR PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES BY TYPE OF SETTING, FLORIDA, 2005-2016



Source: 2020 Technical Appendix, Demographics Table 23, 2020.

DEMOGRAPHICS OF PERSONS WITH DISABILITIES IN FLORIDA

Age, Gender, Race and Ethnicity

According to the latest U.S. Census Bureau ACS estimates for 2014-2018, the percentage of persons with disabilities in Florida was slightly higher at 13.4 percent of the population compared with 12.6 percent for the U.S. as a whole. By age groups, the percentages were similar, as seen in the following table. The percentage of the population with a disability in Florida's 32 rural counties was higher at 17.9 percent, compared to 13.1 percent in the 35 urban counties (Demographics Table 17, Technical Appendix). By gender, in Florida, 13.4 percent of females and 13.4 percent of males were reported to have a disability as compared to 12.7 percent of females and 12.5 percent of males in the U.S. as a whole (Demographics Table 18, Technical Appendix). Almost 80 percent of persons with disabilities in Florida are White and 14.1 percent are Black or African American. Florida's disability statistics are comparable to Florida's overall population of 75.4 percent White persons and 16.1 percent Black or African American persons. The figure below shows the racial composition of Florida's population with disabilities. Hispanics with a disability represent 18.8 percent of Florida's population; this is notably higher than the U.S. as a whole at

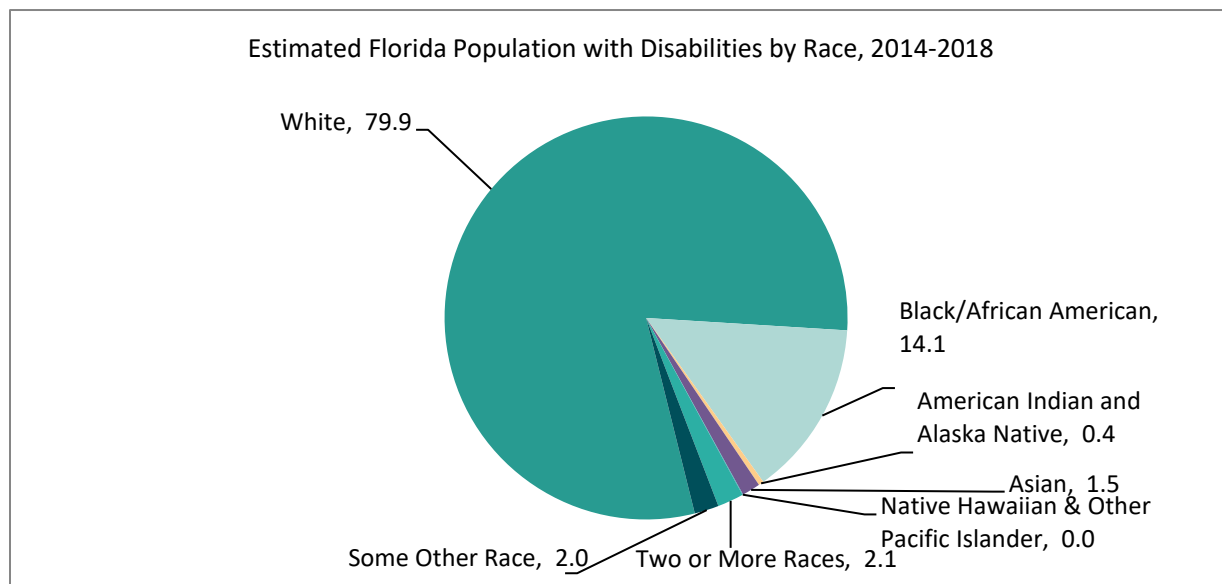
12.6 percent. When examining the urban versus rural divide of Hispanics and Latinos, 19.8 percent of those who reside in an urban county had a disability, while 6.4 percent of those residing in a rural county had a disability (Demographics Table 19, Technical Appendix).

TABLE 2. POPULATION WITH DISABILITIES BY SELECT AGE GROUPS, FLORIDA AND UNITED STATES, 2014-2018

Area	Under 5 Years of Age			5 – 17 Years of Age		
	Total	Total with a Disability	percent with a Disability	Total	Total with a Disability	percent with a Disability
Florida	1,105,204	8,203	0.7	2,997,564	169,567	5.7
United States	19,852,138	150,682	0.8	53,611,721	2,903,877	5.4
	18 – 64 Years of Age			65 Years and Older		
	Total	Total with a Disability	percent with a Disability	Total	Total with a Disability	percent with a Disability
Florida	12,006,098	1,208,053	10.1	3,859,065	1,201,772	33.4
United States	196,138,799	20,276,199	10.3	46,424,983	16,461,324	35.5

Source: 2020 Technical Appendix, Demographics Table 17, 2020.

FIGURE 4. ESTIMATED FLORIDA POPULATION WITH DISABILITIES BY RACE, 2014-2018



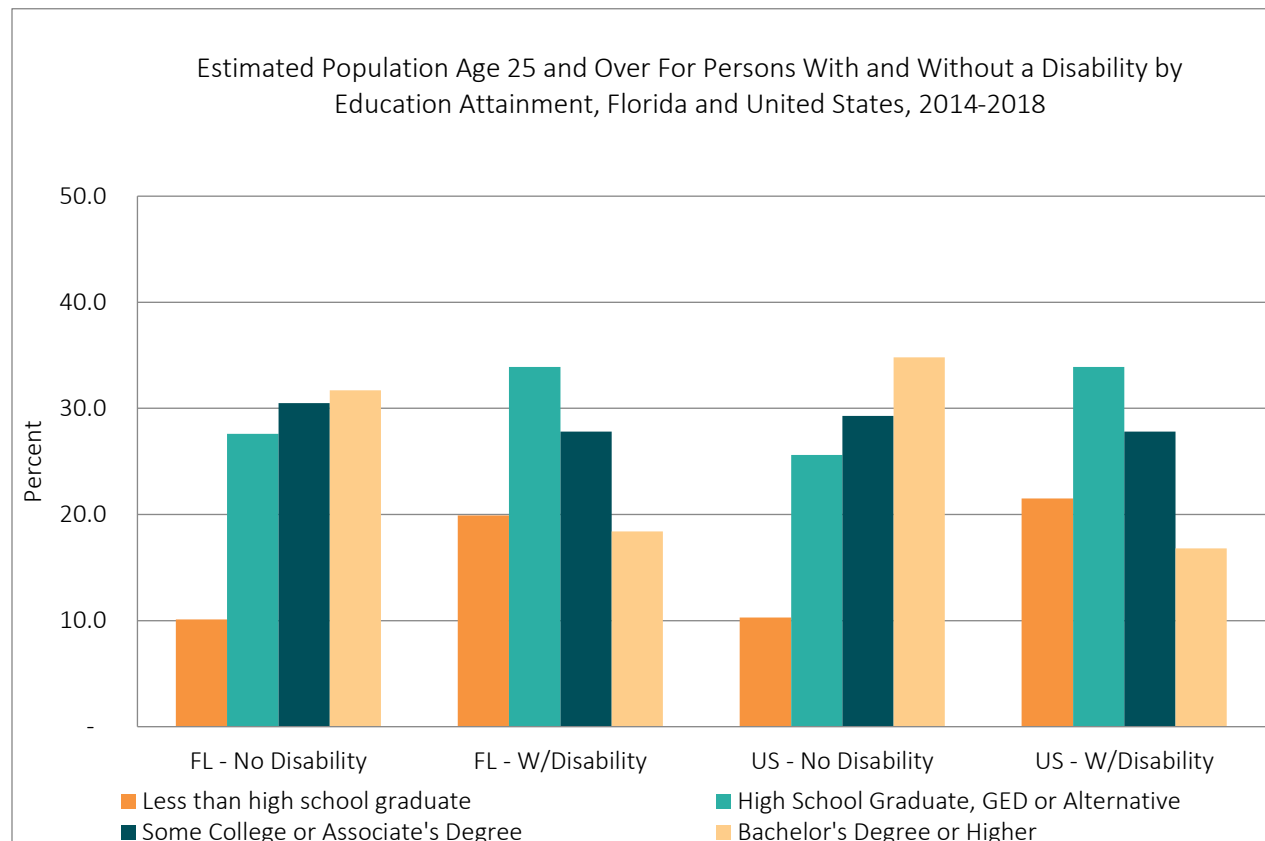
Source: 2020 Technical Appendix, Demographics Table 19, 2020.

Education, Employment, Earnings and Poverty

For Florida and the U.S. as a whole, 33.9 percent of the population with a disability earned a high school diploma, GED, or alternative as their highest educational attainment. This was followed by 27.8 percent, again both in Florida and the U.S., with some college or an associate's degree as their highest

attainment. More Floridians with a disability earned bachelor's degrees or higher at 18.4 percent compared to the U.S. at 16.8 percent. The comparisons among Florida's population with and without a disability with the U.S. population are shown in the figure that follows.

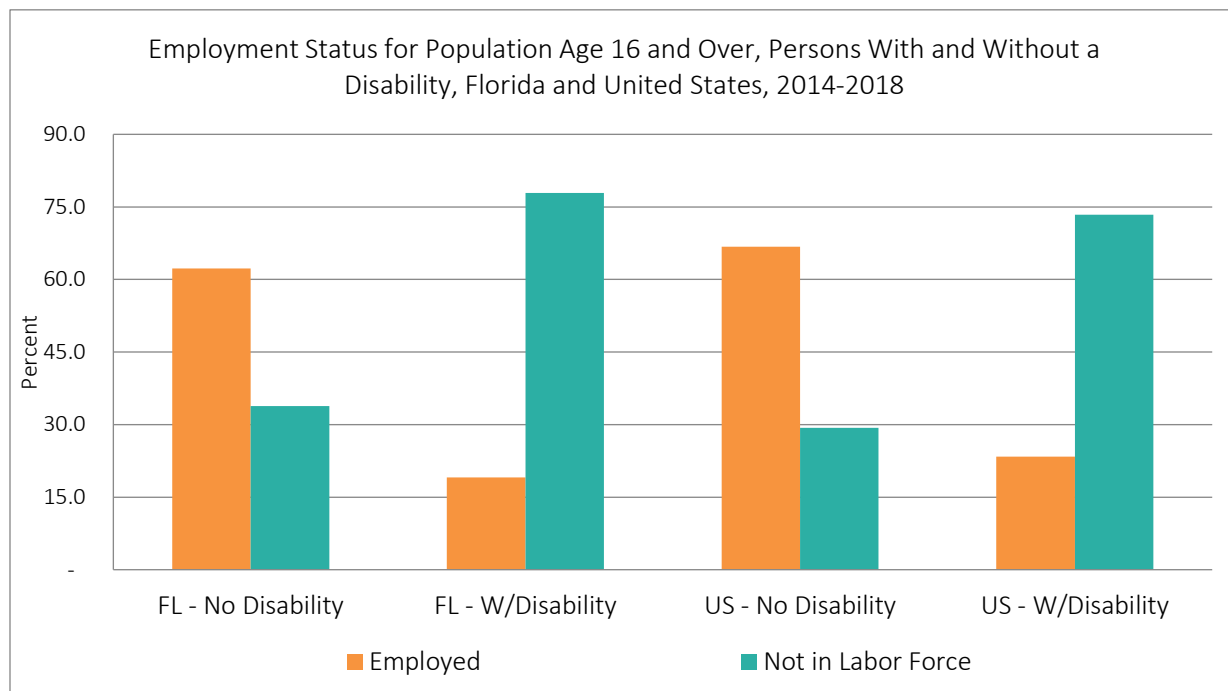
FIGURE 5. ESTIMATED POPULATION AGE 25 AND OVER WITH AND WITHOUT A DISABILITY BY EDUCATIONAL ATTAINMENT, FLORIDA AND THE UNITED STATES, 2014-2018



Source: 2020 Technical Appendix, Demographics Table 20, 2020.

Florida fares worse in the employment status of persons aged 16 and older, both with and without a disability. In Florida, for 2014-2018, the percentage of the population without a disability who were employed was 55.7 percent, compared to 60.4 percent for the U.S. For the same period, Florida's percentage of the population with a disability who were employed was 19.1 percent; it was 23.4 percent for the U.S. (Demographics Table 21, Technical Appendix).

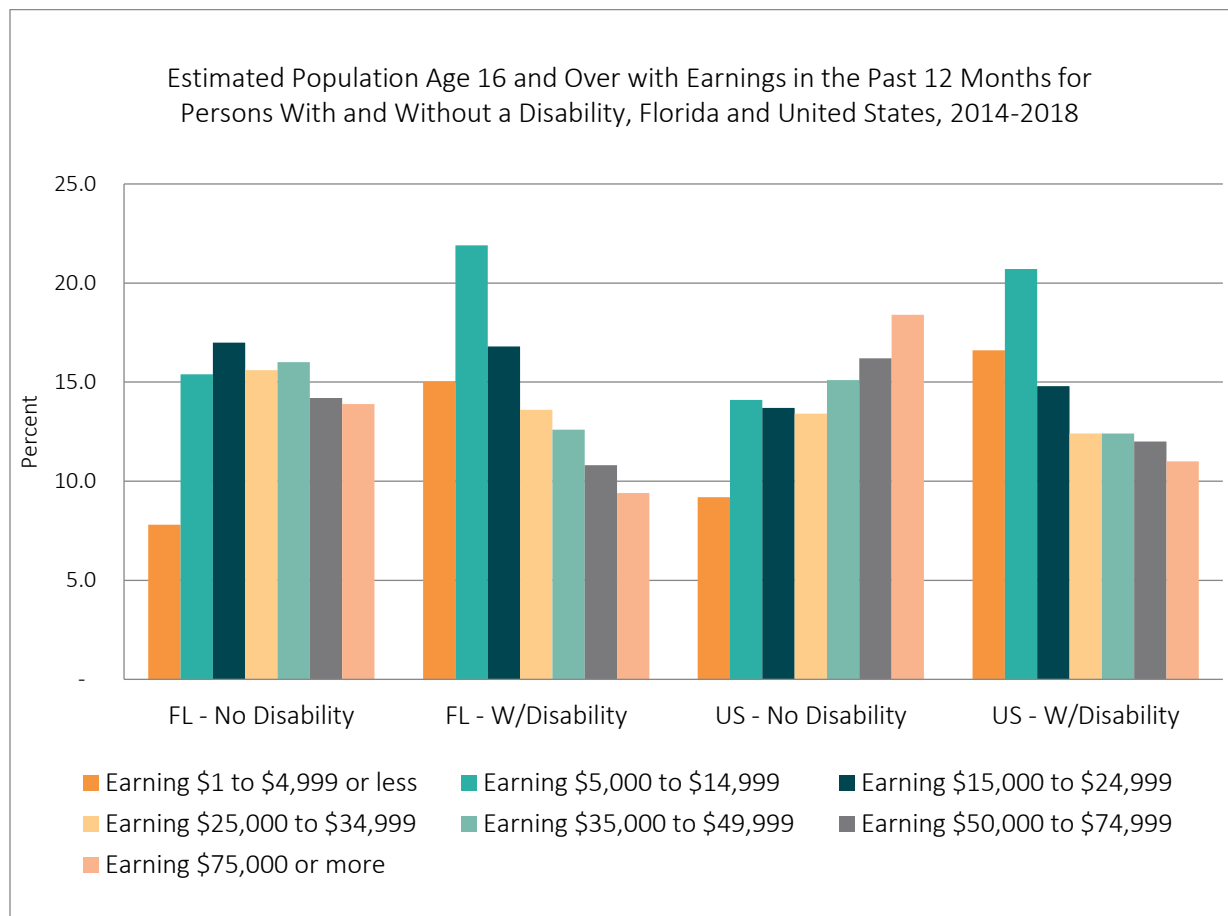
FIGURE 6. EMPLOYMENT STATUS FOR THE POPULATION AGE 16 AND OVER, PERSONS WITH AND WITHOUT A DISABILITY, FLORIDA AND THE UNITED STATES, 2014-2018



Source: 2020 Technical Appendix, Demographics Table 21, 2020.

From 2014-2018, lower percentages of Florida’s population aged 16 and older with a disability had earnings in the past 12 months within the \$50,000 to \$74,999 range (10.4 percent) and \$75,000 or more range (8.6 percent) when compared with the same population nationwide (11.7 and 10.4 percent, respectively). This pattern also held true for Floridians without a disability. For the same timeframe, 15.7 percent of the Florida population with a disability had earnings in the past 12 months of \$4,999 or less compared to 8.3 percent of the same Florida population without a disability (Demographics Table 22, Technical Appendix). A comparison of earnings across the seven income categories for persons with and without a disability in Florida and the U.S. is presented in the next figure.

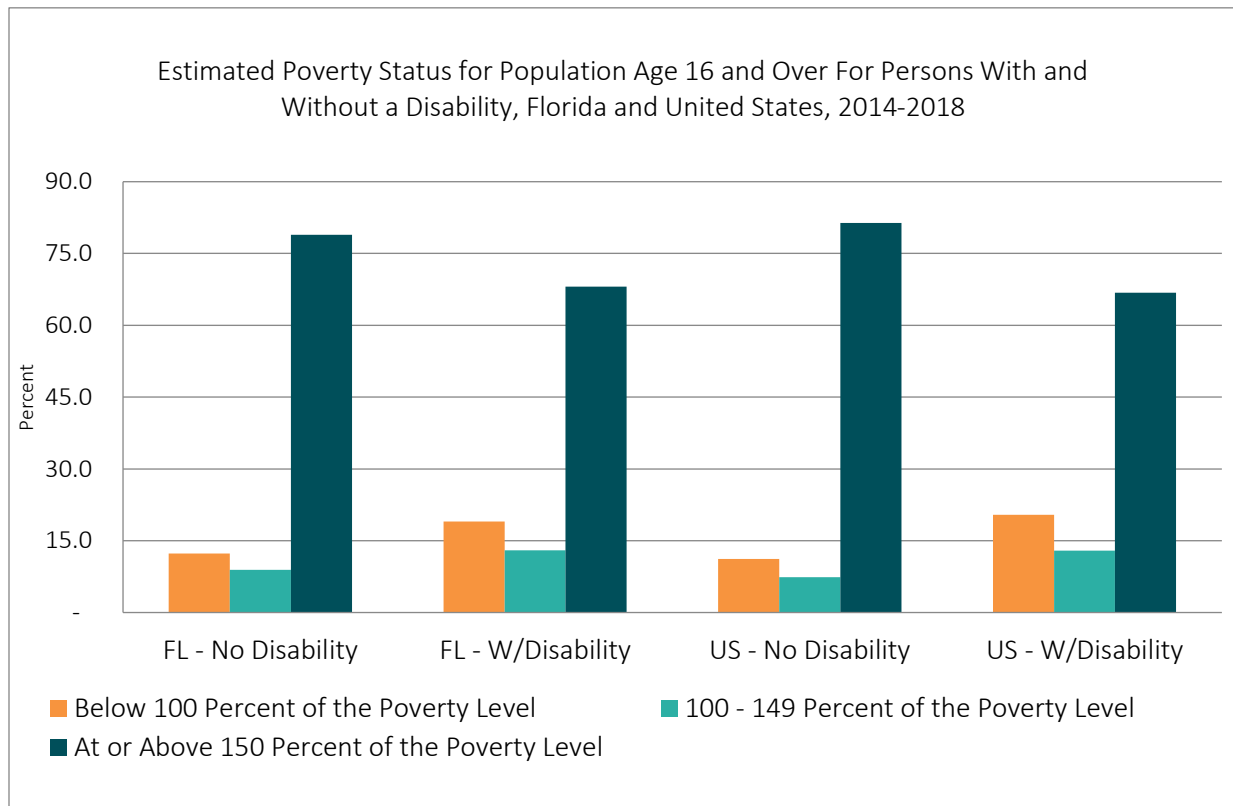
FIGURE 7. ESTIMATED POPULATION AGE 16 AND OVER WITH EARNINGS IN THE PAST 12 MONTHS FOR PERSONS WITH AND WITHOUT A DISABILITY, FLORIDA AND UNITED STATES, 2014-2018



Source: 2020 Technical Appendix, Demographics Table 21, 2020.

The latest data from the U.S. Census Bureau ACS determined the poverty status of 13,967,861 Floridians without disability and 2,563,480 Floridians with a disability. Of those with and without a disability, for three FPL categories, the estimated percentages were similar for Florida and the U.S. as a whole. In Florida, 19.0 percent of persons with a disability were determined to live at or below the FPL, which was slightly lower than for the U.S. as a whole at 20.4 percent (Demographics Table 23, Technical Appendix). When the composition of the population that lives below the FPL, in both Florida and the U.S., is examined by age and disability status, those in Florida under five years of age, with a disability, had the highest rate at 42.3 percent, while the overall U.S. was at 28.9 percent in 2018. However, for all other Florida age groups below the FPL with a disability, the percentages were slightly lower than for the U.S. as a whole.

FIGURE 8. ESTIMATED POVERTY STATUS FOR POPULATION AGE 16 AND OVER FOR PERSONS WITH AND WITHOUT A DISABILITY, FLORIDA AND UNITED STATES, 2014-2018



Source: 2020 Technical Appendix, Demographics Table 23, 2020.

TABLE 3. ESTIMATED PERCENT BY AGE BELOW POVERTY LEVEL WITH AND WITHOUT A DISABILITY, FLORIDA AND UNITED STATES, 2018

Age	With Disability		Without Disability		With and Without a Disability	
	FL	U.S.	FL	U.S.	FL	U.S.
Under 5 Years	42.3	28.9	21.4	19.4	21.5	19.5
5-17 Years	27.1	28.2	18.5	16.9	19	17.5
18-34 Years	23.4	25.6	14.5	14.9	15.1	15.6
35-64 Years	24.2	26.2	9.6	8.1	11.3	10.4
65-74 Years	14.2	13.6	9.3	7.2	10.4	8.8
75+ years	11.7	12.1	10	8.9	10.8	10.4
Total	18.6	20.5	12.8	12.1	13.6	13.1

Source: 2020 Technical Appendix, Demographics Table 24, 2020.

Portrait of the State

In this section, the services, supports and other assistance available to persons with I/DD and their families and caregivers in Florida are described. A review of the following ten categories of service areas develops an understanding of the landscape navigated by persons with I/DD, their families, caregivers, and providers towards assuring the well-being and best quality of life for self-advocates. With Florida's large, diverse, and dynamic population and distinct geography come unique benefits, challenges, gaps, and opportunities. Impacts on under- or unserved populations and those from culturally and linguistically diverse backgrounds are explored as data are available.

HEALTH AND HEALTHCARE

A multitude of community, state, and federal programs are responsible for the access, utilization, and delivery of health and health care services throughout the state of Florida. Some of the major agencies and entities that are involved in the provision and measurement of health and health care access for persons with intellectual and developmental disabilities (I/DD) include, but are not limited to:

- Agency for Persons with Disabilities (APD)
 - iBudget Florida
- Agency for Health Care Administration (AHCA)
 - Medicaid
 - Florida KidCare
 - Healthy Kids
 - MediKids
 - Children's Medical Services Health Plan
- American Community Survey
- Annual Disability Statistics Compendium
- Florida Department of Health
 - Florida Health CHARTS
- Florida State Developmental Disability Centers
 - Sunland
 - Tacachale
- Florida Association of Healthy Start
- Early Steps
- Florida Maternal Infant and Early Childhood Home Visiting Initiative (MIECHV)
- Henry J. Kaiser Family Foundation
- National Core Indicators (NCI)
- University of Wisconsin, Population Health Institute, County Health Rankings
- U.S. Census Bureau

While this section does not address every agency or entity in its entirety, each functions as a vital deliverer of health and health care services.

Some of the data reviewed throughout this section were only available at the statewide level. However, WellFlorida was able to partition some out at county and regional levels, plus the inclusion of an urban versus rural divide, in certain cases. In keeping with FDDC's recommendation, the state's 67 counties were separated into six different Regions: Southeast, Southern, Central, Suncoast, Northeast, and Northwest. The following subsections seek to represent and reflect the key findings of the secondary data analyses conducted. The respective data tables can all be found within the Technical Appendix provided and will be sourced as (Health __, Technical Appendix) for these purposes.

INSURANCE TYPES

It is imperative to note that with the implementation of the Patient Protection and Affordable Care Act (ACA), the state of Florida chose not to expand Medicaid, which in turn, would have made more individuals in the state eligible for the program based on their income. Because of this, Florida has a much higher percentage of individuals with no insurance coverage compared to the United States as a whole. There is a lack of existing data regarding persons with intellectual or developmental disabilities (I/DD) that are enrolled in private insurance coverage. For that reason, the data discussed in this section is applicable to any type of disability.

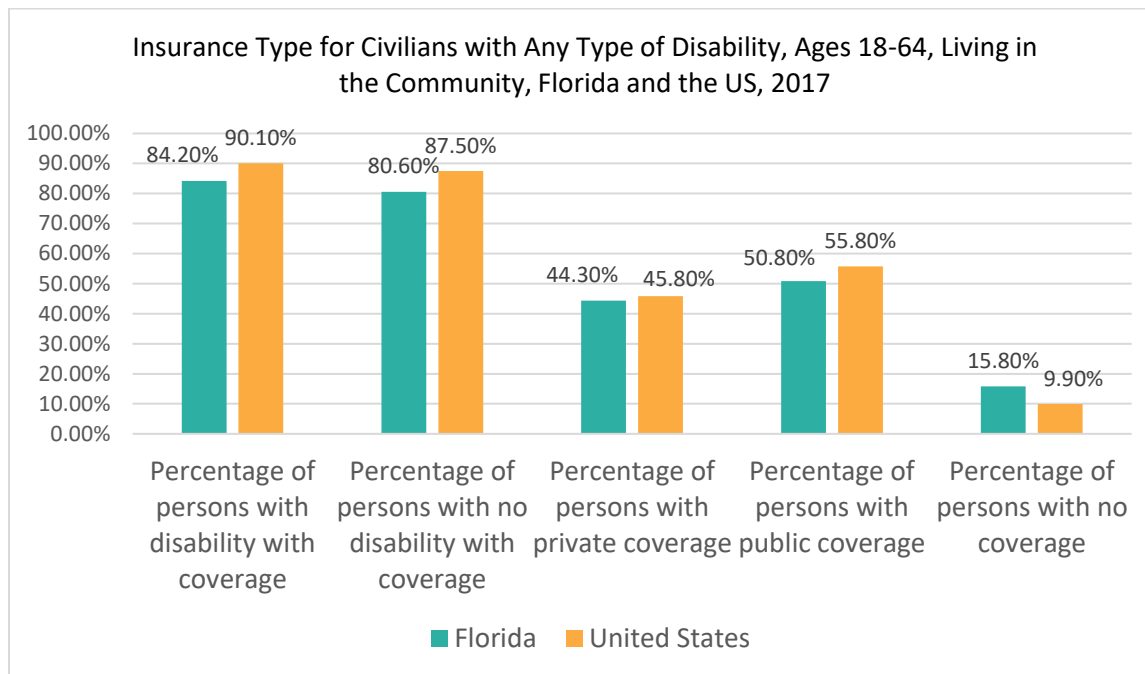
According to the *Annual Disability Statistics Compendium: 2018*, 9.9 percent of the United States' population of persons with a disability are not insured (Health 6, Technical Appendix). However, Florida's percentage of persons with a disability with no coverage, at all, is approximately 15.8 percent (Health 6, Technical Appendix).

When comparing persons with any type of disability to those without a disability, persons with a disability have higher coverage percentages. In Florida, the percentage of persons with a disability with coverage was 84.2, while the United States was 90.1 percent (Health 6, Technical Appendix). The percentage of persons without a disability with coverage was 80.6 percent and 87.5 percent in Florida and the U.S., respectively (Health 6, Technical Appendix).

When examining coverage types, the percentage of persons with private coverage in Florida and the US was 44.3 and 45.8 percent, respectively (Health 6, Technical Appendix). In Florida, the percentage of persons with any type of disability with private coverage was 44.3 percent (Health 6, Technical Appendix). In the US, the percentage of persons with any type of disability with private coverage was 45.8 percent. In contrast, the percent of Floridians with disabilities with public coverage was 50.8, while the US was 55.8 percent (Health 6, Technical Appendix).

Florida falls behind the national average in both private and publicly-funded insurance, indicating that the absence of one does not guarantee the other. Although Florida does have higher coverage percentages for persons with disabilities than those without, the persons who are insured are still not insured at a rate that is commensurate with the rest of the United States, either privately or publicly.

FIGURE 9. INSURANCE TYPE FOR CIVILIANS WITH ANY TYPE OF DISABILITY, AGES 18 – 64, LIVING IN THE COMMUNITY, FLORIDA AND THE US, 2017



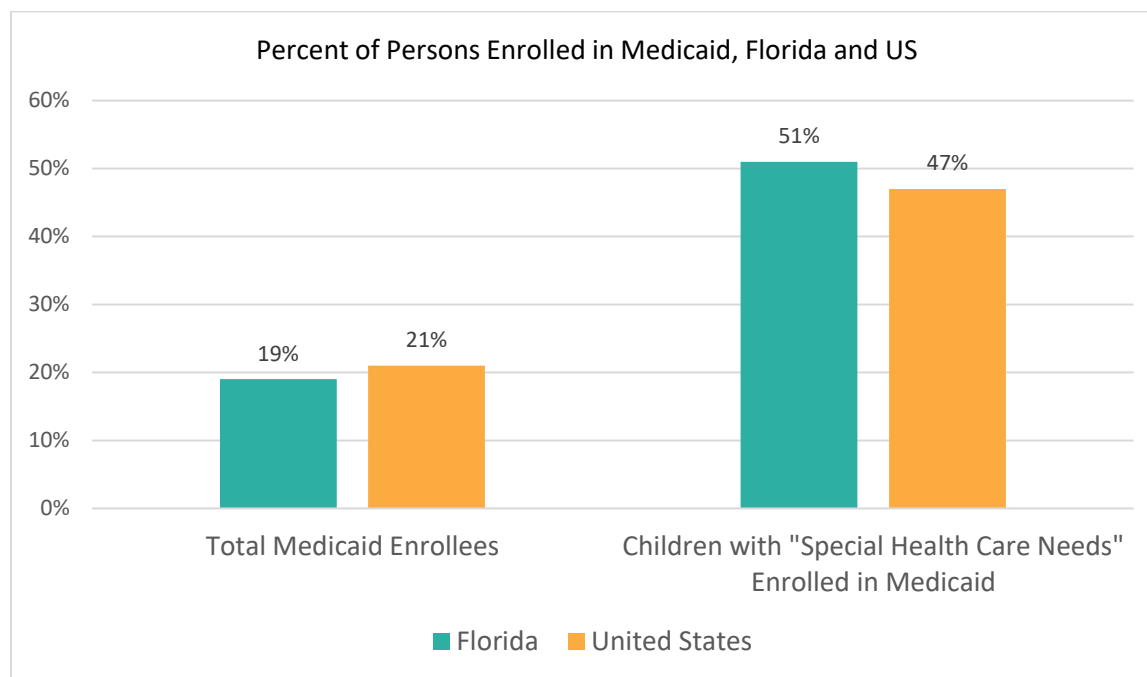
Source: Lauer, 2018

MEDICAID

The state of Florida operates and provides health insurance coverage to approximately 3.78 million Floridians (Health 7, Technical Appendix) through its Statewide Medicaid Managed Care (SMMC) program. The SMMC program is comprised of three separate entities: Managed Medical Assistance (MMA), Long-Term Care (LTC), and Dental. The transition to managed-care enrollment of Medicaid beneficiaries has captured approximately 78 percent of enrollees (approximately 2.99 million). In comparison, nearly 22 percent (approximately 844,000) of Medicaid beneficiaries receive care through typical, fee-for-service Medicaid.

As of December 2019, there were 3,779,655 Floridians enrolled in Medicaid (Health 7, Technical Appendix). Approximately 19 percent of Floridians are enrolled in Medicaid, whereas the national average is 21 percent (Kaiser Family Foundation, 2019). The Henry J. Kaiser Foundation reported that approximately 57 percent of Florida's 2017 childbirths were financed by Medicaid. According to a June 2019 issue brief from the Kaiser Family Foundation, 51 percent of "children with special health care needs" are covered by Medicaid in the state of Florida, compared to the national average of 47 percent (Musumeci, 2019).

FIGURE 10. PERCENT OF PERSONS ENROLLED IN MEDICAID, FLORIDA AND US

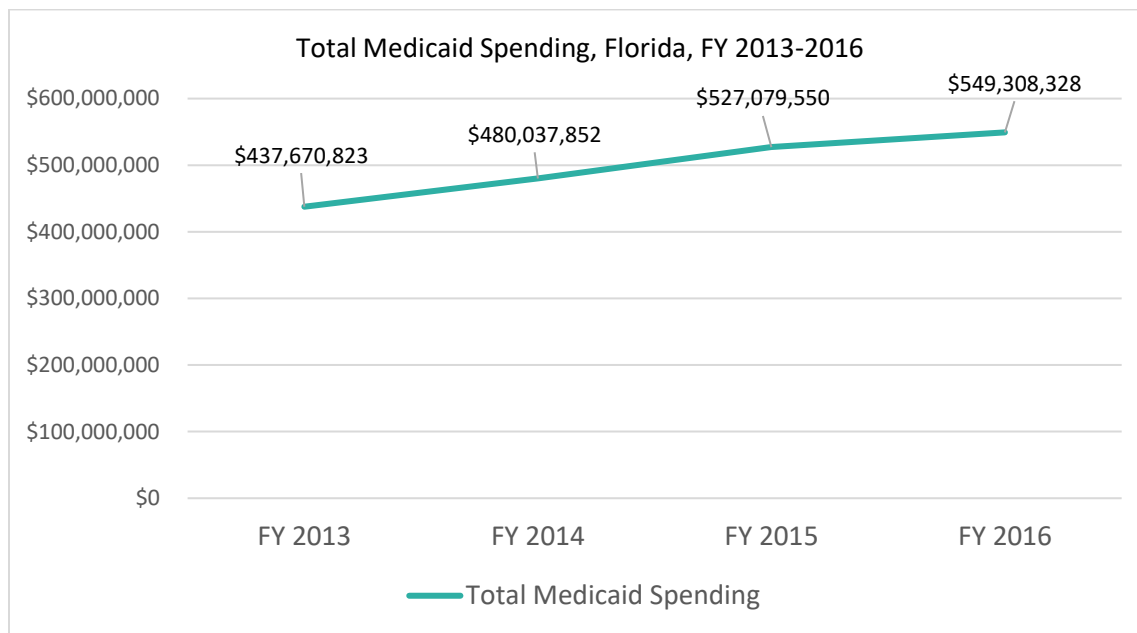


Source: Kaiser Family Foundation, 2019; Musumeci, 2019

The Children's Medical Services (CMS) Network, operated by WellCare, is the managed-care delivery system of Medicaid to children with special health care needs in the state of Florida. As of December 2019, 59,874 children are enrolled in the CMS plan, which includes, but is not limited to, children with I/DD.

Florida's total Medicaid expenditures have been on the rise in recent years. Between Fiscal Years 2013 and 2016, expenditures have increased from \$437,670,823 (in thousands of dollars) to \$549,308,238 (in thousands of dollars) (Health 8, Technical Appendix).

FIGURE 11. TOTAL MEDICAID SPENDING, FLORIDA, FY 2013 - 2016



Source: Eiken, 2018

LONG-TERM SERVICES AND SUPPORTS (LTSS)

The United States' Medicaid Long-Term Services and Supports (LTSS) is a compilation of programs housed under what is known as Home and Community-Based Services (HCBS). These services are comprised of: Section 1915(c) waiver services, Community First Choice, rehabilitative services, and institutional services, such as nursing facilities and intermediate care facilities for persons with intellectual disabilities (ICF/IID) (Eiken, 2018). While each of these services would grant monetary provisions from the federal government, it is at the discretion of the individual state to determine which services they choose to operate.

HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER

Of the above-mentioned services, the state of Florida gives persons with I/DD only two pathways to receive home or community-based care under Medicaid, either through a Section 1915(c) waiver or within an ICF/IID. As an alternative to institutionalization in an ICF/IID, Medicaid Waivers for persons with I/DD began in the early 1980s (Thach, 2018). The preference for persons with I/DD to live within their community, rather than in an institution, has continued to grow over the years.

Eiken et al. (Eiken, 2018) detailed each state's profile of services in a report produced for the Centers for Medicare and Medicaid Services (CMS), titled *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*. This report served as one of the principal data sources for the purposes of this section. The data used to furnish the report comes directly from CMS-64 reports that are then examined by the Medicaid Innovation Accelerator Program at IBM Watson Health. When data collection and analysis began for this project, this report was, and still remains to be, the most recent government-

approved report regarding Long-Term Services and Supports in the United States. The FY 2016 report, as well as previous years, can be retrieved from <https://www.medicaid.gov/> site.

Florida's version of the Section 1915(c) waiver, the iBudget Florida waiver, was signed into law in 2010 under the 2009-2010 General Appropriations Act (Florida Agency for Persons with Disabilities, 2012). The iBudget Florida is currently, and since its inception, has been operated by the Agency for Persons with Disabilities (APD). As of October 2019, there are 34,919 persons receiving services through the iBudget (Delia, P. and Gerbrant, B., 2020).

Currently, the system utilizes individual choice, as well as the support of an individual's family/caretaker and a Waiver Support Coordinator (WSC). The WSC is responsible for overseeing the process of receiving support from the iBudget, once the individual has been accepted for services under the APD's eligibility criteria. The criteria, taken from the Agency for Health Care Administration's website (Florida Agency for Health Care Administration, 2021), is as follows:

- Meet the eligibility requirements in accordance with Chapter 393, F.S.
- Meet the Level of Care criteria for placement in an ICF/IID
- Be eligible for Medicaid under one of a variety of categories described in the Florida Medicaid Provider General Handbook
- Be diagnosed with one or more of the following qualifying disabilities:
 - The individual's intelligence quotient (IQ) is 59 or less; or
 - The individual's IQ is 60-69 inclusive and the individual has a secondary handicapping condition that includes: Down syndrome; Cerebral palsy; Prader-Willi Syndrome; Spina bifida; Epilepsy; Autism; or ambulation, sensory, chronic health, and behavioral problems; or has an IQ of 60-69 inclusive and the individual has severe functional limitations in at least three major life activities including self-care, learning, mobility, self-direction, understanding and use of language, and capacity for independent living; or
 - The individual is eligible under the category of Autism, Cerebral Palsy, Down Syndrome, Prader-Willi Syndrome or Spina bifida and the individual has severe functional limitations in at least three major life activities including self-care, learning, mobility, self-direction, understanding and use of language, and capacity for independent living.

HCBS WAIVER ALTERNATIVE

The Consumer Directed Care Plus (CDC+) Waiver exists as a program alternative to the iBudget (HCBS) waiver. It is a long-term care program that involves the person throughout the entire process, such that they are leading the planning of their supports and services, with greater control of the supports and services. Participants of the CDC+ waiver are able to choose:

- What is being purchased

- Who provides the supports and services
- When they will be provided, as well as the quantity of supports/ services
- Where they will be provided
- How they will be provided

Eligibility criteria for persons who wish to utilize CDC+ program are as follows:

- Be a current consumer under the Medicaid Waiver program
- Live in a family home or own home
- Select a representative (if one is needed)
- Complete CDC+ trainings
- Pass readiness review test with a score of 85 percent or better
- Select a Waiver Support Coordinator trained to provide CDC+ consultant services

IBUDGET WAITING LIST

The iBudget waitlist first reached over 20,000 persons in May of 2011. The wait list's large and historically growing numbers are fueled by a limited budget as dictated by the Florida Legislature. More details about the iBudget waiting list can be found below, in *Analysis of State Issues and Challenges*, under "Waiting Lists." Note that the terms waiting list, wait list, and waitlist are used interchangeably by federal, state, and local agencies referenced in this report.

PREVENTIVE SCREENINGS

Data were analyzed from the National Core Indicators' (NCI) state-specific report. NCI is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The NCI is a survey conducted to assess the availability and quality of person-centered, community-based services and supports for persons with I/DD. The data are gathered through an Adult In-Person Survey, as well as Family Surveys.

The Adult In-Person Survey is conducted face-to-face and is administered to persons who are 18 and older that receive services from the state. The Family Surveys are conducted via a mail-in response system and are administered to family members of persons who are receiving services from the state. There are three different kinds of Family Surveys, which are detailed below:

- Adult Family Survey: Respondents have an adult family member with I/DD (18+) living with them in the family home.
- Family Guardian Survey: Respondents have an adult family member with I/DD (18+) living outside of the family home. Respondents may also be non-family legal guardians, as long as they don't live with the person receiving supports.

- Child Family Survey: Respondents have a child with I/DD (under age 18) living with them in the family home.

The data collected from these surveys is used to:

- Assess individual satisfaction and experience with supports
- Track key outcomes across multiple years
- Compare outcomes to other states and to the average across states
- Improve DD system performance

NCI surveys seek to help states measure the following elements:

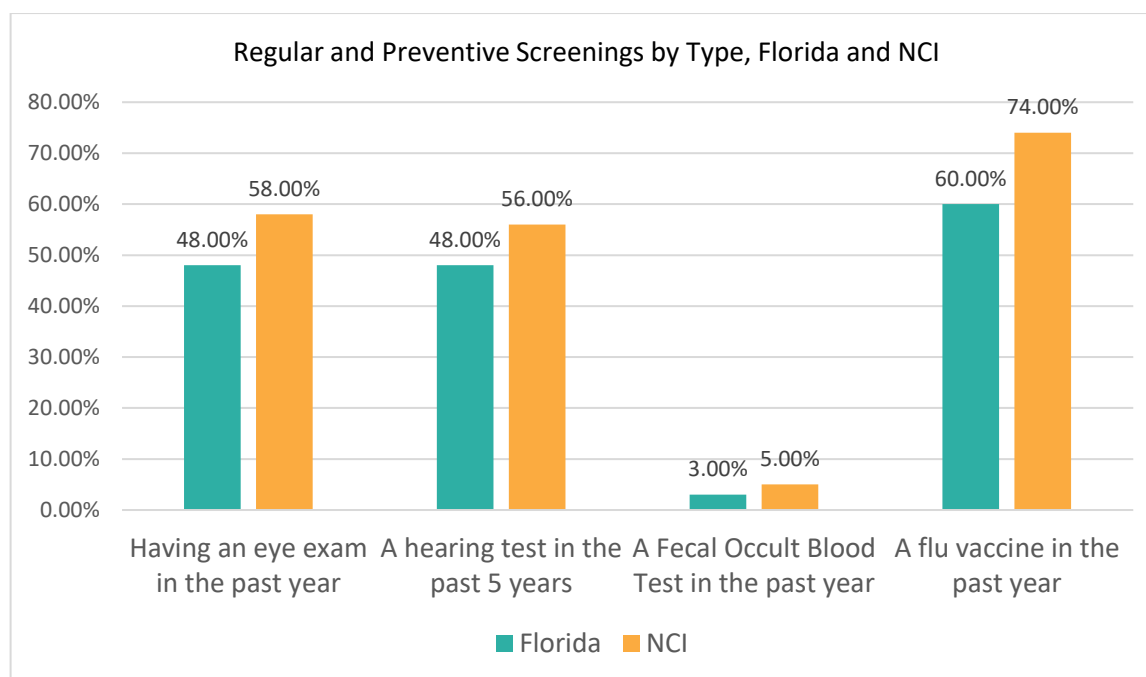
- Self-determination
- Service coordination and access
- Relationships and community inclusion
- Rights, choices and decision-making
- Employment status and goals
- Health, welfare, and safety

There were 967 persons surveyed in Florida and 25,568 surveyed across the nation for the NCI Adult In-Person survey. This section of the survey asked questions regarding regular and preventive screenings, which are based on the following measures:

- Has a primary care doctor or practitioner
- In poor health
- Had a complete physical exam in the past year
- Had a dental exam in the past year
- Had a Colonoscopy in the past 10 years
- Had a Flexible Sigmoidoscopy in the past 5 years or Fecal Occult Blood test in the past 3 years
- Had an eye exam in the past year
- Had a hearing test in the past 5 years
- Had a Pap test in the past 3 years
- Had a mammogram test in the past 2 years
- Had a Fecal Occult Blood test in the past year
- Has never had a colorectal cancer screening
- Had a flu vaccine in the past year

When comparing the state of Florida to the NCI national average, Florida surpassed the average in most elements, excluding four. The four elements in which Florida did not meet or surpass the average were: having an eye exam in the past year (48.0 versus 58.0 percent); a hearing test in the past 5 years (48.0 to 56.0 percent); a Fecal Occult Blood test in the past year (3.0 to 5.0 percent); or a flu vaccine in the past year (60.0 to 74.0 percent) (Health 3, Technical Appendix).

FIGURE 12. REGULAR AND PREVENTIVE SCREENING BY TYPE, FLORIDA AND NCI



Source: National Core Indicators, 2019

MEDICATIONS

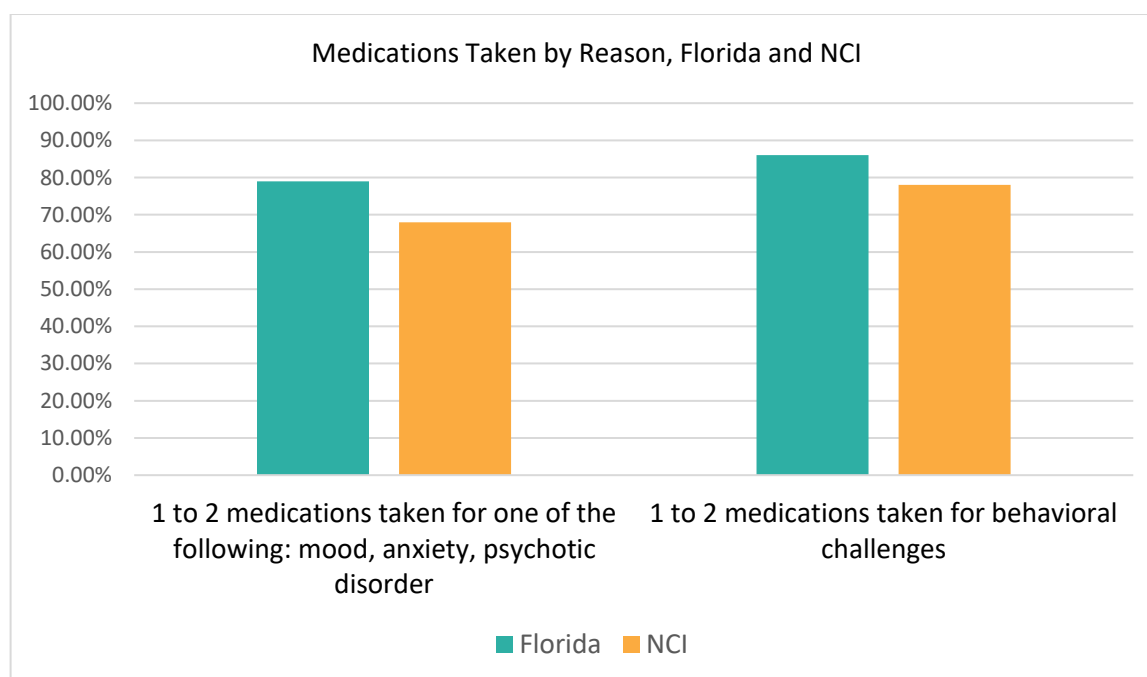
Data regarding medications consumed by persons was also analyzed from the NCI Adult In-Person survey. The population and sample size were the same as previously noted. This section of the survey, regarding medications taken and their respective reason, are based on the following measures:

- Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge
- Takes medication for mood, anxiety, psychotic disorder and/or behavioral challenge
- Takes medication for a behavioral challenge
- Number of medications taken for at least one of the following: mood, anxiety, psychotic disorder (1-2 medications)
- Number of medications taken for at least one of the following: mood, anxiety, psychotic disorder (3-4 medications)
- Number of medications taken for at least one of the following: mood, anxiety, psychotic disorder (5-10 medications)
- Number of medications taken for at least one of the following: mood, anxiety, psychotic disorder (11 or more medications)

- Number of medications taken for behavioral challenges (1-2 medications)
- Number of medications taken for behavioral challenges (3-4 medications)
- Number of medications taken for behavioral challenges (5-10 medications)
- Number of medications taken for behavioral challenges (11 or more medications)
- Has a behavioral plan
- Take medication for behavior challenges and has a behavior plan

When comparing the state of Florida to the NCI national average, Florida did not meet or surpass the average in most factors, excluding two. The two elements in which Florida surpassed the average were: number of medications taken for at least one of the following: “mood,” “anxiety,” “psychotic disorder” (1-2 medications) (79.0 and 68.0 percent); and “number of medications taken for behavioral challenges” (1-2 medications) (86.0 and 78.0 percent) (Health 4, Technical Appendix).

FIGURE 13. MEDICATIONS TAKEN BY REASON, FLORIDA AND NCI



Source: National Core Indicators, 2019

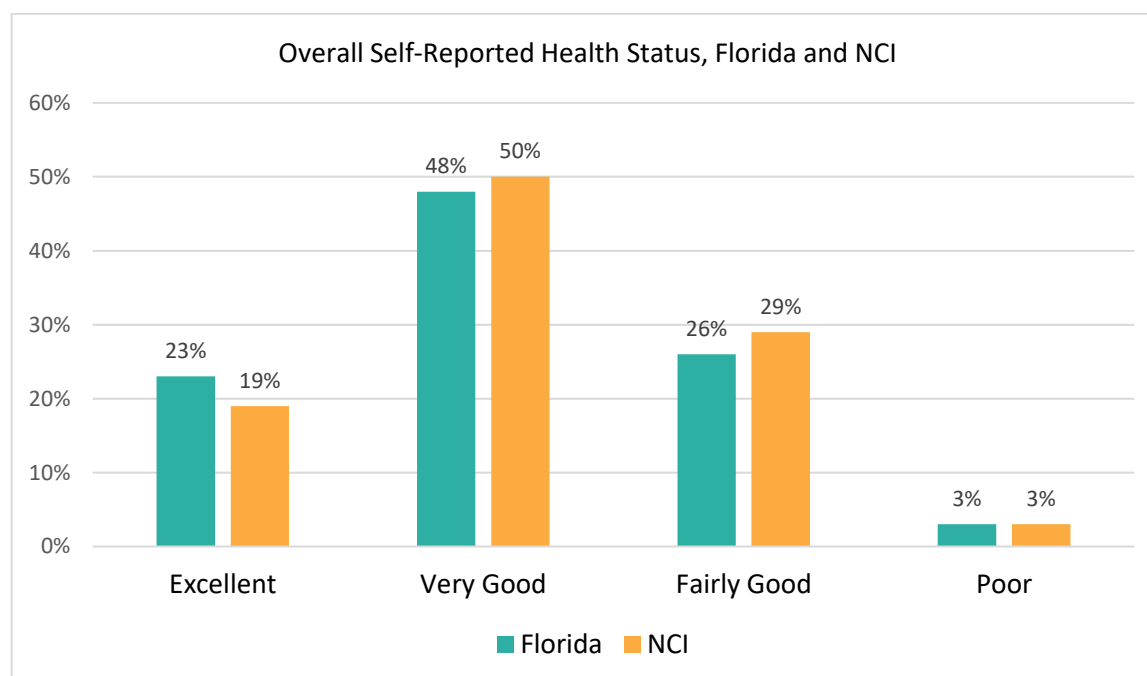
SELF-REPORTED HEALTH STATUS

The data for this subsection was again analyzed from the NCI In-Person Survey. There were 755 persons surveyed in Florida and 20,080 surveyed across the nation. This portion of the survey, regarding self-

reported overall health status, has four classifications: “Excellent,” “Very Good,” “Fairly Good,” and “Poor.”

When comparing Florida to the national average, there was some variance as to how healthy an individual viewed oneself. Those who thought of themselves to be in “Excellent” health were 23 percent (Florida) and 19 percent (national average). Of the Floridians surveyed, 48 percent viewed their health as “Very Good,” in comparison to the national average of 50 percent. Other individuals perceived their health to be “Fairly Good” (26 percent of Floridians and 29 percent nationally). However, Florida and the national average of those who saw their health as “Poor” were the same, at 3 percent of individuals surveyed (Health 5, Technical Appendix).

FIGURE 14. OVERALL SELF-REPORTED HEALTH STATUS, FLORIDA AND NCI, 2017-18



Source: National Core Indicators, 2019

COUNTY HEALTH RANKINGS

The County Health Rankings are a key component of the Mobilizing Action Toward Community Health (MATCH), a collaboration project between the Robert Wood Johnson Foundation and the University of Wisconsin Population Health Institute. Counties receive a rank relative to the health of other counties

in the state. Counties having high ranks (e.g., first or second) are considered to be the “healthiest.” Health is viewed as a multifactorial construct. Counties are ranked relative to the health of other counties in the same state on the following summary measures:

- Health Outcomes—rankings are based on an equal weighting of one length of life (mortality) measure and four quality of life (morbidity) measures.
- Health Factors—rankings are based on weighted scores of four types of factors:
 - Health behaviors (9 measures)
 - Clinical care (7 measures)
 - Social and economic (9 measures)
 - Physical environment (5 measures)

Throughout the years, some County Health Rankings methodology and health indicators have changed. Thus, caution is urged in making year-to-year comparisons. The data are useful as an annual check on health outcomes, contributing factors, resources and relative status within a region and state. The County Health Rankings add to data a community can consider in assessing health and determining priorities.

Both of the overall Health Outcomes and Health Factors, and their associated measures, are given for the year 2020. There is major variation within each region, as some have considerably high rankings, as well as low.

Most notable is the disparity found within the Northeast Region. The Northeast Region is comprised of twenty counties, the most of a single region throughout the state. In regard to Overall Health Outcomes, this region boasts the state’s “healthiest” county, St. Johns, and also the state’s least healthy county, Union (Health 1, Technical Appendix). Within the Overall Health Outcomes score, the “mortality/ length of life” and “morbidity/ quality of life” scores for St. Johns are 3 and 1, respectively; for Union, the scores are 67 and 58, respectively (Health 1, Technical Appendix). While St. Johns did not achieve the highest score for mortality/ length of life, it was the best score within the region.

The Overall Health Factors score places St. Johns again as the “healthiest,” but Putnam County as the least healthy (Health 1, Technical Appendix). Each of the individual Health Factors scores (health behaviors, clinical care, social and economic, and physical) were also provided. St. Johns scored 8, 2, 1, and 25 (Health 1, Technical Appendix) in the aforementioned categories, respective to the order in

TABLE 4. COUNTY HEALTH RANKINGS, HEALTH OUTCOMES AND HEALTH FACTORS BY NORTHEAST REGION, 2020

	Health Outcomes			Health Factors				
	Overall	Mortality/ Length of Life	Morbidity/ Quality of Life	Overall	Health Behaviors	Clinical Care	Social & Economic	Physical
Northeast Region (20 Counties)								
Alachua	26	9	43	5	22	1	13	13
Baker	49	55	50	41	63	28	31	26
Bradford	64	59	64	49	56	55	41	41
Clay	27	22	27	19	35	24	5	38
Columbia	61	58	63	50	58	41	47	32
Dixie	63	63	62	62	67	58	59	17
Duval	45	46	45	34	38	18	34	31
Flagler	17	20	18	22	17	15	29	20
Gilchrist	42	38	42	43	51	51	35	4
Hamilton	58	53	61	63	64	54	63	10
Lafayette	39	40	28	42	41	63	23	43
Levy	59	60	56	58	54	56	52	56
Madison	62	45	66	56	45	47	56	61
Nassau	33	39	12	9	29	10	4	37
Putnam	66	66	65	67	66	50	64	60
St. Johns	1	3	1	1	8	2	1	25
Suwannee	54	42	60	52	57	62	38	29
Taylor	60	61	59	53	60	42	50	39
Union	67	67	58	47	65	43	39	12
Volusia	40	41	30	27	24	16	32	50

Source: University of Wisconsin, Population Health Institute, 2020

which they were listed. Putnam scored 66, 50, 64, and 60 Health 1, Technical Appendix), respective to the order in which they were previously listed. St. Johns received the top scores for health behaviors and social and economic factors.

However, Alachua County received top scores for clinical care (Health 1, Technical Appendix), which is likely impacted by the presence of the University of Florida and its UF Health initiatives within the county. The top-scoring “physical” factor counties and their rankings were: Gilchrist (4), Hamilton (10), Union (12), Alachua (13), Dixie (17), Flagler (20), and then St. Johns (25) (Health 1, Technical Appendix).

NURSING HOME AND HOSPITAL BEDS

The data was taken from Florida CHARTS and was able to be separated into regions, with both rural and urban counties, as well as the total state numbers. Each region has counts for the following total beds: nursing home, hospital, acute care, rehab, intensive residential treatment facility (IRTF), adult psychiatric, child adolescent psychiatric, and adult substance abuse. Upon reviewing the data from

Florida's Health CHARTS, there was an indication of a disparity between rural and urban counties in each bed type, excluding total nursing home beds.

The state of Florida operates 83,779 nursing home beds, 64,585 hospital beds, 52,174 acute care beds, and 2,674 rehab beds (Health 2, Technical Appendix). There are 140 IRTF beds, 4,377 adult psychiatric beds, 644 child adolescent psychiatric beds, and 376 adult substance abuse beds (Health 2, Technical Appendix).

When comparing rural and urban counties, there are 6,088 rural nursing home beds and 77,691 urban nursing home beds. Rural counties have 1,595 hospital beds and 1,561 acute care beds (Health 2, Technical Appendix). Rural counties have zero rehab, IRTF, adult/ child adolescent psychiatric, or adult substance abuse beds (Health 2, Technical Appendix). Urban counties have 77,691 nursing home beds, 62,990 hospital beds, and 50,613 acute care beds (Health 2, Technical Appendix). Urban counties house all of Florida's rehab, IRTF, adult/ child adolescent psychiatric, and adult substance abuse beds (Health 2, Technical Appendix).

The statewide nursing home beds rate is 399.8 per 100,000; 308.2 per 100,000 for hospital beds; 248.9 per 100,000 for acute care beds; and 12.8 per 100,000 for rehab beds (Health 2, Technical Appendix). The rate for ITRF beds is 0.7 per 100,000; 20.9 per 100,000 for adult psychiatric beds; 3.1 per 100,000 for child adolescent psychiatric beds; and 1.8 per 100,000 for adult substance abuse beds (Health 2, Technical Appendix).

Rural counties have a nursing home beds rate of 522.5 per 100,000; 136.9 per 100,000 for hospital beds; and 134.0 per 100,000 for acute care beds (Health 2, Technical Appendix). In comparison, urban counties have a nursing home beds rate of 392.5 per 100,000; 318.3 per 100,000 for hospital beds; and 255.7 per 100,000 for acute care beds (Health 2, Technical Appendix). Because rural counties do not have any rehab, IRTF, adult/ child adolescent psychiatric, or adult substance abuse beds, the rate per 100,000 in urban counties is slightly higher, as a result of population adjustment.

TABLE 5. TOTAL NURSING HOME BEDS AND HOSPITAL BEDS BY TYPE, RATES PER 100,000 POPULATION, RURAL AND URBAN COUNTIES AND FLORIDA, 2018

	Total Nursing Home Beds		Total Hospital Beds		Acute Care		Rehab	
	Number of Beds	Rate Per 100,000 Population	Number of Beds	Rate Per 100,000 Population	Number of Beds	Rate Per 100,000 Population	Number of Beds	Rate Per 100,000 Population
Rural Counties	6,088	522.5	1,595	136.9	1,561	134.0	0	0.0
Urban Counties	77,691	392.5	62,990	318.3	50,613	255.7	2,674	13.5
Florida	83,779	399.8	64,585	308.2	52,174	248.9	2,674	12.8
	Intensive Residential Treatment Facility (IRTF)		Adult Psychiatric		Child Adolescent Psychiatric		Adult Substance Abuse	
	Number of Beds	Rate Per 100,000 Population	Number of Beds	Rate Per 100,000 Population	Number of Beds	Rate Per 100,000 Population	Number of Beds	Rate Per 100,000 Population
Rural Counties	0	0.0	0	0.0	0	0.0	0	0.0
Urban Counties	140	0.7	4,377	22.1	644	3.3	376	1.9
Florida	140	0.7	4,377	20.9	644	3.1	376	1.8

Source: Florida Department of Health, 2018

SUMMARY

In summary, this section, combined with the Technical Appendix, provides a synopsis of available health and health care services for individuals with intellectual disabilities. While insurance coverage does not guarantee the accessibility of services or better health outcomes, those with I/DD in Florida disparately lack the ability to utilize the health care system because they are not as frequently insured, as compared to the national average. Any type of data relevant to individuals with private coverage is much more difficult to procure, although individuals are privately and publicly insured at similar rates. A majority of available data is reflective of all disability types, indicating that there is a need to better the collection and reporting of health data specifically for persons with I/DD.

EMPLOYMENT

A host of agencies work towards assuring that persons with disabilities, including I/DD, can train and find placement in jobs and also receive the services and supports to maintain or improve their employment prospects.

The Florida Department of Education Division of Vocational Rehabilitation (VR) leads Florida's federal and state partnership efforts to help persons with disabilities prepare for, secure, and advance in jobs. VR's programs and services include the Transition Youth Program to help students prepare and plan for post-high school employment; Deaf, Hard of Hearing, and Deaf-Blind Services that include training for both the employee and employer; Supported Employment services that aim to assist those with the most significant disabilities be successful in competitive employment; Independent Living Program services through a statewide network of locally-based Centers for Independent Living (CILs); and the Florida Alliance for Assistive Services and Technology (FAAST) which provides assistive technology devices and services so that persons with disabilities can fully participate in independent living, education, work, and recreation through their lives. VR's employment supports may include transportation, placement, training, or retraining, and use of assistive technology. In 2018-2019, VR served almost 50,000 individuals, including more than 22,000 transition-age youth. VR assisted 5,924 Florida residents in becoming successfully employed (Florida Department of Education, Division of Vocational Rehabilitation, 2019).

Florida's Agency for Persons with Disabilities (APD) offers many programs and services to promote training and employment support for persons with disabilities. The Employment Enhancement Program (EEP) aims to assist individuals on the APD Waiting List and young adults leaving school to obtain competitive employment. In the 2019-2020 Fiscal Year, APD will dedicate \$900,000 from a Legislature and Governor appropriation for these supported employment services. Adult Day Training (ADT) initiatives provide volunteer opportunities, job skills training and job exploration, and access to community services. ADT programs are offered locally by APD partners and stakeholders, including The Arc. Through the iBudget Florida and Home and Community-Based Services (HCBS) Medicaid Waiver, APD offers individual and family training, as well as job supports for those in the Consumer Directed Care Plus (CDC+) program. In 2017-2018, APD reported it had placed 2,957 individuals in competitive employment, representing 5.0 percent of those served by the agency. About 9.2 percent of those receiving ADT services were in competitive employment in 2017-2018; this represents a decrease of about 18.5 percent. For that same period, APD reports that 7,682 individuals who wanted employment were not employed (Employment Table 4, Technical Appendix). In Fiscal Year 2017-2018, the Florida Department of Children and Families (DCF) reported that 2,081 individuals received employment services. DCF's employment services are largely limited to supported employment which includes the

individual placement and support model, and mental health clubhouse services for persons with severe mental illnesses (Employment Table 3, Technical Appendix).

Persons with disabilities in Florida may find services that aid with job supports, worksite accommodations and technology, and career planning from a variety of organizations. The Florida Alliance for Assistive Services and Technology (FAAST), an entity of Florida's VR, administers a statewide program to provide assistive technology group and individual training, device demonstrations, and use instruction, loaning of assistive technology equipment, and funding assistance for the purchase of assistive technology. FAAST also promotes public policy initiatives to educate government and community leaders on the importance of assistive technology to persons with disabilities, their families, and the communities in which they live and work. In 2019, about 5.7 percent of device loans were made to the employment sector and about one (1.0) percent of device demonstrations and trainings were provided to that sector (Assistive Technology Tables 4 and 5, Technical Appendix).

Persons who are blind may seek vocational services through the Florida Division of Blind Services. This state agency provides vocational training, job placement, on-the-job training, orientation and mobility training, career counseling and guidance, and job modification services, including assistive technology.

As an arm of the Department of Economic Development (DEO), Florida's 24 Local Workforce Development Boards support employers and help Floridians gain employment, stay employed, and advance in their careers. Workforce Development Boards offer career and job placement support through their disability employment specialists. For the Fiscal Year 2017-2018, DEO reports serving 41,402 persons with disabilities across Florida with 7,832 persons with disabilities placed in employment (Employment Table 7, Technical Appendix).

The mission of The Able Trust, an organization created by the Florida Legislature to support vocational rehabilitation efforts, is to provide opportunities for successful employment for Floridians with disabilities. The Able Trust focuses on grant support for community organizations to provide training, coaching and job placement; programs to encourage high school youth with disabilities to plan for higher education and employment; and work experience for persons with disabilities. Since its inception in 1990, The Able Trust has distributed more than \$41 million in grant funding for employment support for persons with disabilities in all 67 Florida counties (The Able Trust, 2018).

The Florida Association of Rehabilitation Facilities (ARF) manages the RESPECT of Florida Program. RESPECT works with Florida nonprofit organizations to employ persons with disabilities in the production of products and services sold to state and local government agencies. These products include mops, calendars, and computers, and among the services provided are janitorial and microfilming. In 2017-2018 through the Respect of Florida Program, 1,246 individuals were employed

with an additional 689 individuals in supported employment and 15 in competitive employment (Association of Rehabilitation Facilities, n.d.).

The FDDC Council projects made important impacts in the area of postsecondary transition and employment. Instituted in 2015, Project TOPS (Transition to Postsecondary Institutions) was a three-year program at Robert Morgan Education Center and Technical College that provided supportive strategies for students 18 to 22 years of age with I/DD. In its third year, enrollment increased to 35 students and achieved status as a Florida Postsecondary Comprehensive Transition Program by the Center for Students with Unique Abilities. Through Project Achieve, the Council, in collaboration with Florida State College at Jacksonville and the Duval County School District, created an inclusive career and technical education (CTE) program. Program outcome data show that 83.0 percent of certificate program finishers found paid employment.

The Council supports the Employ Me 1st project of the Institute for Community Inclusion, which maintains this aptly named website that provides information and links to employment-related services. Project SEARCH is designed as a one-year internship program for students with disabilities that is set in a business workplace to facilitate the learning and application of employment and marketable skills. There are 37 Project SEARCH sites in Florida across 26 counties. The Council supports the Employment First Collaborative, as they train employment service professionals using their toolkit specifically developed to assess and identify competency-based training options to improve their capacity to employ persons with disabilities. Employment Options Informed Choice is another one of the training initiatives supported by the Council, that seeks to enhance the skills of those providing employment services to persons with I/DD (Florida Developmental Disabilities Council, n.d.)

VR provides assistance to students with I/DD as they transition from high school to postsecondary education, employment, and careers. Youth Transition – The VR Transition Youth Program, provides assessments and counseling about careers, offers work-readiness skills training, sponsors work-based learning experiences and post-high school counseling to all students, ages 14 to 21 years with documented disabilities. Through the Workforce Innovation and Opportunity Act (WIOA), VR also offers Pre-Employment Transition Services, without requiring that students with disabilities apply or be determined eligible. These services include career exploration counseling, work readiness training, self-advocacy training, postsecondary educational counseling, and community-based work experiences.

Indicators show that in Florida, persons with disabilities in general, and persons with I/DD in particular, are not finding employment to the extent they desire. As noted earlier in this report, about 19.0 percent of persons 16 years of age and older with a disability in Florida are employed, while more than 62 percent of persons without a disability are in the workforce (Demographics Table 21, Technical

Appendix). In 2018 in Florida, about 34 percent of civilians with disabilities of all types were employed, compared to 75.6 percent for civilians in Florida without disabilities. Of civilians in Florida with cognitive disabilities, only 24.4 percent were employed, which was lower than the national rate of 27.8 percent (Employment Table 8, Technical Appendix). In 2017-2018 service data, APD documents that more than 7,600 clients who wanted employment were unemployed (Employment Table 4, Technical Appendix). National Core Indicators (NCI) data for Florida point to lagging performance in employment for persons with I/DD. Only 10.0 percent of NCI Florida participants reported having a paid community job compared to 18.0 percent nationwide. About six (6.0) percent said they have a group job with or without publicly funded support, whereas nationwide that figure was 27.0 percent. Fewer Floridians reported attending a day program or workshop at 48.0 percent contrasted with 57.0 percent nationally. Only 19.0 percent of Floridians reported having community employment as a goal in their service plan, while 29.0 percent nationally strive for employment (Employment Table 1, Technical Appendix). Post-school outcome data from the Florida Department of Education, Bureau of Exceptional Education and Student Services point to achievements for students with disabilities. In 2016-2017, of the students with disabilities who exited Florida public schools the previous year, 51.0 percent were found enrolled in higher education or competitively employed. This represents a gain of 16.0 percent in one academic year (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019).

INFORMAL AND FORMAL SERVICES AND SUPPORTS

People with developmental disabilities and their families and caregivers in Florida are served by numerous governmental, private, nonprofit, volunteer, and service organizations, agencies, and associations. The following informal and formal services and supports may complement programs, services, and resources described in other sections of this assessment report. In addition, please refer to the *Technical Appendix* for more detailed service and program performance metrics.

HEALTH AND SOCIAL SERVICES

Florida's Agency for Persons with Disabilities (APD) is tasked specifically with serving the needs of Floridians with developmental disabilities. In addition to administering the iBudget Florida program and extensive Medicaid Home-Based and Community Services (HBCS) described earlier, APD's Home and Community Services Administration provides other supports and resources. These include support coordination, adult day training services, adult and child respite services, specialized assessments and therapies along with needed equipment and supplies. In Fiscal Year 2018-2019, APD reported serving 1,700 persons with disabilities in the Adult Supported Employment Program and more than 10,000 were served by the Adult Transportation program (Florida Agency for Persons with Disabilities, 2019).

The Florida Department of Children and Families (DCF) partners with local communities to protect vulnerable populations, promotes strong families, and supports self-sufficiency, recovery, and resiliency for those individuals and families. DCF's Florida Abuse Hotline accepts reports 24 hours a day, seven (7) days a week of known or suspected child abuse, neglect, or abandonment, or suspected abuse, neglect, or exploitation of a vulnerable adult. The hotline accepted 493,319 calls in 2018-2019; this count includes reports impacting persons with I/DD. In the same timeframe, DCF reported that 48,968 investigations were undertaken, which included the investigation of abuse, neglect, or exploitation of persons with disabilities and the frail elderly. Also in that year, 5,654 people, including those with disabilities and the elderly, received protective supervision and protective intervention services from DCF. (Florida Department of Children and Families, 2019). Florida Statutes Chapter 415 Adult Protective Services and Chapter 410, Aging and Adult Services, along with DCF's Statewide Operating Procedures (CFOP 140-2 – 140-11) for Adult Protective Services provide the supportive policy and legal authority for protecting vulnerable adults including those with I/DD (Florida Department of Children and Families, n.d.).

The Children's Special Health Care section of the Florida Agency for Health Care Administration (AHCA) reports that more than 93 percent of families were satisfied with the care provided under the program in 2018-2019. AHCA is responsible for Florida's Medicaid program that serves nearly five (5) million people and licenses almost 50,000 health care facilities. Under Title XXI of the Social Security Act, State Children's Health Insurance Program (SCHIP), AHCA reports that 216,350 children were enrolled in the KidCare program in 2018-2019, with 28,089 also enrolled in the MediKids program, and 11,732 in the Children's Medical Service (CMS) Network. CMS is a division of the Florida Department of Health, offering six (6) programs for children with special health care needs. Through its Medicaid Services for individuals in 2018-2019, AHCA reports that more than two (2) million children received the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services and that 73 percent of eligible children completed the EPSDT screenings (Florida Agency for Health Care Administration, 2019).

The Florida Department of Elder Affairs (DOEA) serves more than five (5) million residents of Florida who are 60 years of age and older. Most direct services are provided through the Division of Statewide Community-Based Services through 11 Area Agencies on Aging (also called Aging and Disability Resource Centers, ADRCs) and local service providers. DOEA offers a wide range of programs that address general and specific needs of elders, including those persons with disabilities. Through the Comprehensive Assessment and Review for Long-Term Care Services (CARES) program, the medical and long-term care needs of seniors are assessed by healthcare professionals to determine the appropriate level of care needed and care options. In 2018, DOEA reported performing 99,247 nursing home applicant assessments. The Program of All-Inclusive Care (PACE) works to provide individuals who

would otherwise qualify for Medicaid nursing home placement with home and community-based services. Individuals in PACE may have their needs managed through a single provider. In 2019, there were 2,565 PACE slots statewide (Florida Department of Elder Affairs, 2019). The Office of Public and Professional Guardians (OPPG) is found within DOEA and provides guardianship services to those who cannot afford guardian services or have no able family or friends to serve in that role. In Fiscal Year 2017-2018, there were 550 registered professional guardians and 17 contracted public guardian offices. In the same period, OPPG served 3,846 individuals of all abilities (Florida Department of Elder Affairs, Office of Public and Professional Guardians, 2019). The many programs offered through the DOEA include the Elder Abuse Prevention Program, Home Care for the Elderly Program, and the National Family Caregiver Support Program.

Families and caregivers of persons with I/DD may access resources and services through Healthy Families Florida, a home visiting program for expectant parents and families with newborns experiencing stressful life situations. Healthy Families Florida partners with DCF and The Ounce of Prevention Fund of Florida to place services in all 67 Florida counties.

EDUCATION AND EMPLOYMENT

The Multiagency Network for Students with Emotional/Behavioral Disabilities (SEDNET) is a network of 19 regional projects working to assure the provision of quality care for students with or at-risk for emotional and/or behavioral challenges. The SEDNET regional stakeholders voice the needs of students in each school district, work to improve service coordination, and involve parents and students in local systems of care. SEDNET is funded through the Florida Department of Education (DOE), Bureau of Exceptional Education and Student Services (BEESS). The Institute for Small and Rural Districts (ISRDC) is also funded through the Florida DOE BEESS to provide technical assistance for positive outcomes for students with disabilities and their families in the 48 small, rural school districts in Florida (Institute for Small and Rural Districts, Florida Department of Education, Bureau of Exceptional Education and Student Services, n.d.). The Florida Inclusion Network (FIN), in conjunction with Florida State University, and supported by the Florida DOE BEESS, is another resource for students with disabilities and their families and caregivers. FIN offers the Peers as Partners in Learning curriculum and planning guide to school districts, principals, and teachers to assist with implementation of this peer learning program (Florida Inclusion Network, n.d.).

The University of South Florida's Florida Center for Inclusive Communities' Positive Behavior Interventions and Support (PBIS) initiative works to enhance Florida's school district capacity to implement positive behavioral interventions within a multi-tiered system of support. PBIS offers technical assistance to school districts that can support school-wide, classroom, group, and individual

student behavioral interventions (University of South Florida, Florida Center for Inclusive Communities, Positive Behavior Interventions and Support, n.d.).

The Florida Center for Students with Unique Abilities (FCSUA) at the University of Central Florida was established in 2016 to implement requirements of the Florida Postsecondary Comprehensive Transition Program Act (2019 Florida Statutes, 1004.6495, 2020). In 2018-2019, the Florida Postsecondary Comprehensive Transition Program (FPCTP) served 121 students with unique abilities at nine (9) FPCTP program sites with services such as postsecondary education program selection, application process assistance, and financial aid assistance and transition planning for students. Institutions are offered planning, program development, and grants for FPCTP expansion as well as assistance with community coalition building. In 2018-2019 an additional three (3) FPCTP sites were approved through the Florida DOE. The FCSUA maintains the FCSUA website (Florida Center for Students with Unique Abilities, n.d.), conducts webinars and information sessions, and hosts an annual meeting to promote FPCTP resources for students and faculty (Florida Center for Students with Unique Abilities, College of Community Innovation and Education, University of Central Florida, 2019).

Florida's Centers for Autism and Related Disabilities (CARD) serve persons with current a diagnosis of Autism Spectrum Disorders (ASD) and related disabilities, along with their families and professionals who care for them. Seven (7) regional CARD sites are funded by the Florida Legislature through the Florida DOE. Sites include Florida Atlantic University, Florida State University, University of Central Florida, the University of Florida at Gainesville and Jacksonville, University of Miami, and the University of South Florida. CARDS help individuals and families find local services and support, provide training on working with individuals with ASD, and consult with caregivers and professionals to identify the best ways to serve persons with ASD-related disabilities (Florida Center for Autism and Related Disabilities, n.d.).

INDEPENDENT LIVING, HOUSING, AND TRANSPORTATION

The Division of Vocational Rehabilitation (VR) of the Florida DOE manages the independent living program for persons with disabilities. The program provides services through a network of private nonprofit, non-residential, locally-based and consumer-controlled Centers for Independent Living (CILs). There are 16 CILs in Florida that offer four (4) categories of core services, which include: information and referral, independent living skills training, individual and systems advocacy, and peer counseling. CILs may offer other services to support independent living, as determined by community needs and resources. In Fiscal Year 2018-2019, the Florida DOE reports serving 17,151 clients with disabilities with independent living services (Florida Department of Education, 2019).

The Florida Association of Centers for Independent Living (FACIL) provides support and resource development for Florida's 16 CILs. Among the services offered are information and referral, independent living skills development, peer mentoring and networking, advocacy and transition services. In Fiscal Year 2017-2018, FACIL served 22,780 individuals with information and referral services. During the same period, independent living skill development services were delivered to 4,930 individuals, and 3,080 individuals were served by peer mentoring and networking supports. Another 3,790 individuals benefited from FACIL's transition services (Florida Association of Centers for Independent Living, n.d.).

Residential Options of Florida (ROOF), a nonprofit organization, was established by the Florida Inclusive Housing Task Force of FDDC. ROOF informs people with I/DD about housing options. ROOF also identified the need for tools to help with planning for independent living and navigating the often complex housing options. Another of ROOF's interests is the collection of housing-related data to better inform planning and advocacy efforts in the interests of people with I/DD. Resources for self-advocates, families, housing providers, and disability service providers are available on their web site (Residential Options of Florida, n.d.).

ADVOCACY, VOLUNTEERISM, AND RECREATION

The Florida Self-Advocates Network'D (FL SAND) is a statewide, nonprofit organization focused on expanding self-advocacy throughout Florida, via service as a united voice on important issues for self-advocates and all persons with I/DD. FL SAND works with local grassroots efforts, forms and supports legislative platforms, and networks with local business and civic partners to raise awareness and promote inclusivity. Florida Self-Advocacy Central, an arm of FL SAND, is the communication hub to connect self-advocates, their families, and others who support them. FL SAND lists 21 local chapters throughout Florida that provide resources and opportunities in the areas of self-advocacy, policy and legislative action, employment, transportation, healthcare, financial independence, and self-advocacy events.

Disability Rights Florida serves persons with disabilities in Florida through advocacy, education, investigation, and litigation to protect and advance rights, dignity, equal opportunity, choice, and self-determination. Disability Rights Florida provides free and confidential services to individuals and supports statewide initiatives.

Although volunteer opportunities are available throughout Florida, according to NCI data, at 21.0 percent, fewer Floridians with developmental disabilities volunteer than their national counterparts (31.0 percent; Employment Table 1, Technical Appendix). Volunteer Florida welcomes persons of all interests and abilities to serve others. Volunteer Florida operates the state's official volunteer

opportunities registry through its electronic platform, Volunteer Connect. Floridians can participate in national service in programs such as AmeriCorps VISTA and Senior Corps, in-state emergency management volunteer efforts, and numerous local projects. Volunteer Florida Foundation raises funds to support Volunteer Florida and the Governor’s special initiatives such as Black History Month and Hispanic Heritage Month events. The Florida Faith-Based and Community-Based Advisory Council functions as a formal advisory body to the Executive Office of the Governor and to the Legislature. This council partners with state agencies to provide volunteer opportunities to communities (Florida Faith-Based and Community-Based Advisory Council, n.d.).

Organizations that support and promote recreation services for persons with disabilities in Florida include the Florida Disabled Outdoors Association, Florida Special Olympics, and the Florida State Park Service, along with its national counterpart, the National Park Service, and local (county and city) parks and recreation agencies. Accessibility is priority and a main focus for these organizations. Information on accessible features and amenities at national, state, and local parks and recreation centers are posted on their websites and available on-site (Florida State Park Service, n.d.). Advocacy and policy change for inclusivity and accessibility are emerging issues for the Florida Disabled Outdoors Association.

INTERAGENCY INITIATIVES

A shared vision and mission to improve the quality of life for persons with I/DD and their families and caregivers are at the core of each of these federally-assisted state interagency initiatives. Collaboration and cooperation are important to: leverage resources, close service gaps, avoid duplication, implement best and innovative practices, promote supportive policy, and advocate for positive change for all people and communities. Collaboration and cooperation are also vital tenets for the organizations that serve persons with I/DD. Outlined below are the missions and directives of the numerous interagency collaborations among agencies and/or groups in Florida that serve persons with I/DD.

TABLE 6. INTERAGENCY INITIATIVES

Interagency Initiative Title	Description
<i>State-established interagency initiatives: (listed alphabetically)</i>	
Aging and Disability Resource Centers (ADRCs)	The Florida Department of Elder Affairs’ eleven (11) Area Agencies on Aging operate the ADRCs which serve as a single, coordinated system for information and service access for all Floridians seeking long-term care support. Through the ADRCs Floridians have access to information and assistance with federal and state benefits.

Interagency Initiative Title	Description
Early Learning Advisory Council (ELAC) Office of Early Learning (OEL), Florida Department of Education	ELAC members bring business and community-focused perspectives to early learning. The ELAC makes recommendations to OEL on using local, state and federal funds, content of professional development training programs, and best practices.
Florida Alliance for Assistive Services and Technology (FAAST)	Florida's number one resource for Assistive Technology (AT) providing information and assistance, AT device demonstrations, AT group training, AT device loans, AT funding assistance. FAAST is administered through the Florida Department of Education Division of Vocational Rehabilitation. In the past year, FAAST loaned 3,825 devices, held 1,543 AT trainings, reported a 447 percent return on investment, and held 4,385 device demonstrations. Source: FAAST (n.d. (Florida Alliance for Assistive Services and Technology, n.d.)
Florida Association of Centers for Independent Living (FACIL)	FACIL is a capacity building advocacy organization that provides support and resource development for 16 Centers for Independent Living (CILs) throughout Florida. CILs are community-based, nonprofit agencies that empower persons with disabilities to move from dependence to independence
<ul style="list-style-type: none"> Information and referral 	Connection to services, FY 17-18 served 22,780 individuals
<ul style="list-style-type: none"> Independent living skills 	Assistance with development of skills including money management, goal setting, accessing transportation, finding and using assistive technology, employment readiness and social skills, FY 17-18 served 4,930
<ul style="list-style-type: none"> Peer mentoring 	Peer support and mentoring in group settings and for individuals, FY 17-18 served 3,080 individuals
<ul style="list-style-type: none"> Advocacy 	Assistance in areas of individual and systems advocacy. Education for consumers and communities on roles and responsibilities under the Americans with Disabilities Act (ADA), FY 17-18 served 4,040 individuals

Interagency Initiative Title	Description
<ul style="list-style-type: none"> Transition Services 	Facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary education and/or employment, FY 17-18 served 3,790 individuals (Florida Association of Centers for Independent Living, n.d.)
Florida Commission for the Transportation Disadvantaged (CTD)	Florida's CTD is a coordinated statewide effort for shared ride services. Transportation services are available in all 67 Florida counties. Federal, state and local agencies work together to provide transportation to medical appointments, employments, education and other life sustaining services.
Florida Department of Economic Opportunity (DEO) Local Workforce Development Boards (24 in Florida)	Workforce development boards assist employers and job seekers with employment services, labor market information and provide disadvantaged adults, youth, dislocated workers and individuals transitioning to employment.
Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT)	Florida Department of Health, Children's Medical Services Early Steps Program maintains the FICCIT to advise the program by identifying resources, assuring accountability and promoting interagency collaboration
Florida Rehabilitation Council (FRC), Florida Department of Education	The FRC is committed to increasing employment, enhancing independence, and improving the quality of life for Floridians with disabilities. The FRC works with the Division of Vocational Rehabilitation in planning and developing statewide rehabilitation programs and services and promotes high standards and expectations for every area of service delivery
State Advisory Committee for Education of Exceptional Students (SAC), Florida Department of Education	The SSTIC is a state-level interagency team designed to facilitate inter-organizational understanding, identify needs grounded in data, identify and realign capacity building resources, facilitate collaboration and avoid duplication, and share responsibility and planning to improve secondary transition.
<i>Other established interagency initiatives and federally-assisted interagency initiatives:</i>	

Interagency Initiative Title	Description
Family Care Council Florida (FCCF) 13 area councils in Florida	FCCF educates and empowers individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities (APD), to bring quality services to individuals with dignity and choice.
Florida Association of Rehabilitation Facilities (ARF)	Florida ARF promotes the interests of individuals with disabilities by acting as a public policy change agent. ARF promotes and serves the interests of community human service providers. Florida ARF member agencies provide a full spectrum of services to support the various needs of individuals with disabilities including employment, community-based supports, residential, therapies, and educational services. ARF administers multi-million dollar programs annually that result in employment of thousands of individuals with disabilities and houses a cadre of professionals providing a variety of services to its members and the industry.
Florida Employment First Florida	Employment First Florida's overarching goal is to ensure broad participation of stakeholders to ensure systems change for better jobs for persons with disabilities.
Florida Health and Transition Services (HATS) 4 regional councils in Florida	HATS is a program of Florida Department of Health, Children's Medical Services. HATS' mission is to ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs.
Florida Independent Living Council (FILC)	Federal- and state-mandated council that collaborates with the Florida DOE and other state agencies on planning and evaluating the independent living program, preparing annual reports, and conducting public forums.
Florida Children and Youth Cabinet, Office of the Governor	The Cabinet ensures that the public policy of Florida relating to children and youth promotes interdepartmental collaboration and program implementation in order for services designed for children and youth to be planned, managed and delivered in a holistic and integrated

Interagency Initiative Title	Description
	manner to improve the self-sufficiency, safety, economic stability, health and quality of life of all children and youth in Florida.
State Secondary Transition Interagency Committee (SSTIC)	The SSTIC is a state-level interagency team created to facilitate inter-organizational understanding, identify needs using data, realign capacity-building resources, foster collaboration and shared responsibility while avoiding duplication and improve secondary transition.

Source: 2020 Technical Appendix, Interagency Table 1, 2020.

QUALITY ASSURANCE

The Agency for Health Care Administration (AHCA) currently contracts with Qlarant to administer the Statewide Quality Assurance Program to examine the state's developmental disabilities service system. AHCA works in partnership with the Agency for Persons with Disabilities in this endeavor. The quality assurance efforts focus on the Developmental Disabilities Home and Community-Based Services (HCBS) Waiver and the Consumer Directed Care Plus (CDC+) programs. Qlarant conducts periodic person-center reviews (PCR) and provider reviews (PDR) to examine adherence to protocols and aspects of customer service satisfaction. The PCR consists of an interview with the person with a disability, the person's support coordinator, and a review of records maintained by the support coordinator. The components of a PDR include an individual interview, staff interview, observations, service-specific records review, policies and procedures review, and qualifications and training review. Qlarant's third-quarter report, published in May 2018, showed that average scores on all review components (interviews, observations, and records reviews) were at 90 percent or higher. The review identified issues with providers having policies in place for background screening procedures (about 19.0 percent of providers reviewed), and 16.0 percent of providers had elements missing from the required documentation for at least one employee. Qlarant hosts online resource centers for individuals and families and providers, supplies a training center, and convenes an in-person quality council (Qlarant, 2018).

In the spring of 2020, APD announced that it would be launching a new system of Individual Comprehensive Assessment (ICA) tools, processes, and resources that will replace the current Questionnaire for Situational Information (QSI). The ICA will result in quicker access to more actionable information for support coordinators and providers and will ultimately result in a better quality of life

for persons with I/DD, as well as a more efficient processes for the persons and agencies that serve them.

The U.S. Department of Justice, Office for Victims of Crime reports that the rate of violent victimization against persons with disabilities was 2.5 times higher than for persons without disabilities and that 20 percent of crime victims with disabilities believed they were targeted because of their disability. Further, data from 2011-2015 showed that persons with cognitive disabilities suffered the highest victimization rate among the disability types examined for violent crimes, serious violent crime, and simple assault (U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics, 2017).

Persons with I/DD, their families and caregivers can turn to various state agencies and organizations for supports and services related to the prevention of abuse, neglect, exploitation, inappropriate use of restraints and seclusion, and violations of human rights. The Florida Department of Child and Families' (DCF) Abuse Hotline fielded almost half a million calls in Fiscal Year 2018-2019. During that same timeframe, DCF conducted nearly 50,000 investigations, including those that examined potential cases of abuse, neglect, or exploitation of persons with disabilities and the frail elderly. DCF provided protective supervision and protection intervention services to 5,654 persons, including persons with disabilities and the elderly also during that Fiscal Year (Services Table 2, Technical Appendix). Since 2006, the Agency for Persons with Disabilities (APD) has employed the Zero Tolerance training model to educate direct care providers, support coordinators, and any persons providing care or support to an APD client on behalf of the agency or its providers. The curriculum focuses on recognizing and preventing abuse, neglect, and exploitation of persons with I/DD. The Florida Department of Elder Affairs sponsors the Elder Abuse Prevention Program. As previously mentioned, Disability Rights Florida provides investigative and education services to persons with disabilities. Disability Rights Florida formulates legislative priorities and engages in advocacy and education of elected leaders. The Florida Department of Health's (DOH) Violence and Injury Prevention Section funds local services for victims of sexual violence that include crisis intervention, referrals, advocacy and accompaniment, counseling, therapy, and support groups. DOH's Refugee Health Program conducts health assessments and related services for foreign-born victims of trafficking. The Florida Department of Education, Bureau of Exceptional Education and Student Services provides a wealth of information for parents, students, teachers, and the public on topics related to protecting the rights and security of students with disabilities. Among the documents publicly available, some in multiple languages, are: the "Child Abuse Prevention Sourcebook for Florida School Personnel: A Tool for Reporting Abuse and Supporting the Child," "Family Educational Rights and Privacy Act," "Florida Statutes and State Board of Education Rules," "Notice of Procedural Safeguards for Parents of Students with Disabilities," and "Documenting,

Reporting, and Monitoring the Use of Seclusion and Restraint on Students with Disabilities: Information for Parents” (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2020).

TABLE 7. NATIONAL CORE INDICATORS (NCI) ADULT IN-PERSON SURVEY OF ADULTS WITH DEVELOPMENTAL DISABILITIES, RESULTS ON SAFETY, RIGHTS, SELF-DIRECTION-RELATED FACTORS, FLORIDA AND NCI AS A WHOLE, 2017

Factors Related to Safety, Rights, Self-Direction and Service Coordination Participation	Florida	NCI as a Whole
Safety	percent	
Has a least one place where the person feels afraid or scared	10	19
Has someone to go to for help if they feel afraid or scared	97	94
Rights and Respect for Individuals		
Has a key to the home	55	47
Can use phone and Internet when he/she wants	89	91
Staff treat person with respect	94	93
Attended self-advocacy troupe, meeting, conference or event	20	24
Has voted in a local or national election	36	37
Self-Direction		
Can make changes to individual budget or services if needed	97	88
Took part in last service planning meeting	100	98
Was able to choose services they get as part of the service plan	92	79
Service Coordination Participation		
Case manager asks the person what he/she wants	97	88
Understood what was discussed at last service planning meeting	89	84

Source: 2020 Technical Appendix, Quality Assurance, Tables 1 and 2, 2020

EDUCATION AND EARLY INTERVENTION

The Florida Department of Health Children’s Medical Services (CMS) Early Steps is an umbrella program that assists families with high risk or developmentally delayed infants and toddlers obtain the services they need. The program identifies infants early, develops Individualized Family Support Plans (IFSP), and coordinated early intervention services and supports. Individuals with Disabilities Education Act (IDEA) Part C program services fall under the Early Steps umbrella. In 2019, nearly 38,000 children were screened and 18,000 newly enrolled. There were about 57,000 children active in the Early Steps program in that year (Health Table 53, Technical Appendix). In Fiscal Year 2018-2019, about 89.0 percent of infants and toddlers received services within 30 days of consent, 96.0 percent of toddlers exiting the program had received transition services within not more than nine months of their third

birthday, and 95.0 percent of infants and toddlers had made progress towards their IFSP goals (Florida Department of Health Children's Medical Services, 2019). The Children's Forum and Florida's Office of Early Learning sponsor the Help Me Grow Florida program in 31 Florida counties. This program provides free developmental and behavioral screenings for children to eight (8) years of age and connects families to services. Since 2014, Help Me Grow Florida facilitated 23,434 developmental screenings, made 19,437 referrals, and served 23,147 children (Help Me Grow Florida, 2019). Child Find is a service offered through the Florida Department of Education, Bureau of Exceptional Education and Student Services (BEESS), Florida Diagnostic and Learning Resources System (FDLRS). Child Find, working with local school districts, locates children who are potentially eligible for IDEA services and links them to those services. There are 30 Early Learning Coalitions throughout Florida that provide services such as Voluntary Prekindergarten (VPK), school readiness, and childcare resource referrals.

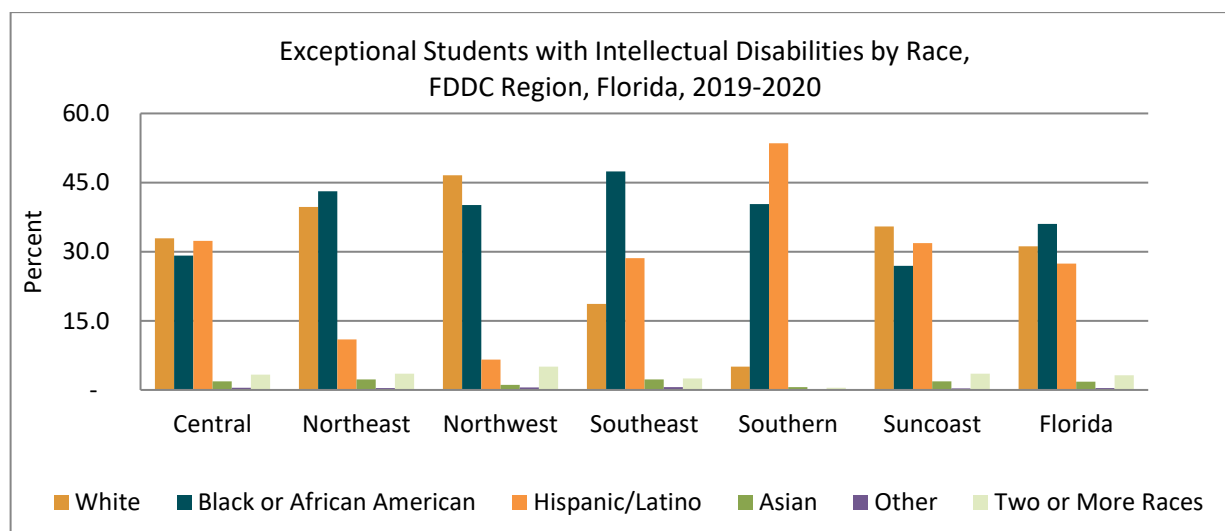
IDEA Part B special education and education services for school-aged children from three (3) to 21 years of age are provided by BEESS. For the school year 2017-2018, there were 349,764 students aged 6 through 21 years who received Part B services in Florida schools. According to the 2019 State Education Agency (SEA) Profile, there were 2,846,857 students in Florida's pre-kindergarten through 12th grade population, of which 14.0 percent, or 401,745, were students with disabilities. Students with intellectual disabilities represent about 7.1 percent of all students with disabilities; that is, students with intellectual disabilities numbered 28,523 in 2019. Race and ethnicity of all students with disabilities and students with intellectual disabilities are shown in the table that follows. Racial composition of Florida's exceptional students with intellectual disabilities by FDDC service region is displayed in the next figure.

TABLE 8. STUDENTS WITH DISABILITIES BY RACE AND ETHNICITY, BY PERCENT, FLORIDA, 2019

Race and Ethnicity	All Students with Disabilities	Students with Intellectual Disabilities
	percent	
White	38	32
Black	25	36
Asian	1	2
American Indian/Alaskan Native	< 1	<1
Native Hawaiian/Other Pacific Islander	<1	<1
Two or more races	4	3
Hispanic	32	27

Source: Florida Department of Education, Bureau of Exceptional Education and Student Services, *State Education Agency (SEA) Profile*, 2019

FIGURE 15. STUDENTS WITH INTELLECTUAL DISABILITIES BY RACE BY FDDC REGION, BY PERCENT, 2019



Source: 2020 Technical Appendix, Education Table 19, 2020.

In 2018-2019, about 76.0 percent of students with disabilities were in regular classes (i.e., spent 80.0 percent or more of the school week with students without disabilities) and 14.0 percent were in separate classes (i.e., spent between 40.0 and 80.0 percent of the school week with students without disabilities). The standard diploma graduation rate in 2017-2018 for Florida students with disabilities was 80.0 percent, a notable increase of 21.2 percent from approximately 66.0 percent in 2016-2017. The dropout rate for students with disabilities fell to 13.0 percent in 2017-2018 from 17.0 and 16.0 percent in 2015-2016 and 2016-2017, respectively. Post-school outcome data in 2016-2017 show 24.0 percent of Florida students with disabilities who exited school the previous year were enrolled in higher education, 51.0 percent were enrolled in higher education or were competitively enrolled, and 59.0 percent were enrolled in higher education or some other postsecondary education or training program or competitively employed (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019).

According to BEESS in 2016-2017, when examined by exceptionality, students with emotional/behavioral disabilities (EBD) were involved in the most incidents of use of restraints at 42.0 percent and seclusion at 55.0 percent, followed by students with Autism Spectrum Disorder at 24.0 percent and 18.0 percent, respectively. In that school year statewide, there were 8,700 restraint incidents involving 3,239 students and 1,351 seclusion incidents involving 503 students. Restraint use increased by about 14.0 percent from the previous school year, while seclusion incidents decreased by

an almost equal percent at 13.6 percent (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2017).

In 2016-2017, 93.4 percent of Florida teachers employed to work with students receiving special education under IDEA Part B were classified as highly qualified; this is on par with the national figure of 93.2 percent (Education Table 13, Technical Appendix). Project Access is one of the Florida Department of Education's discretionary projects and is a statewide effort for professional development that results in more enhanced instructional planning and academic content delivery to students with significant cognitive disabilities. In 2018-2019, through Project Access, more than 2,500 professionals received professional training (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019).

The Florida Statute Section 1002.01(2) definition of a private school stipulates that such an entity is an educational center that includes kindergarten, or a higher grade, and is below the college level. The Florida Department of Education does not license, approve, accredit or regulate private schools, but they are required to provide information annually for inclusion in a statewide school directory. According to the Florida Department of Education's 2018-2019 School Year Private School Annual Report, there were 380,295 students in prekindergarten through 12th grade private school enrollment. This represents about 11.8 percent of the total Florida school enrollment, with the complementary 88.2 percent (2,846,857 students) enrolled in public schools. Private schools in Florida have seen an increase in the number of schools (increased by 39 schools) and the number of students (enrollment increase of 10,129 students) when compared to the previous school year (Florida Department of Education).

During the 2018-2019 school year, more than 31,000 Florida students in grades K-12 with special needs benefited from the McKay Scholarship Program for Students with Disabilities. This program was established to provide the option to attend a public school other than the one assigned, or to extend a scholarship to a private school of choice to students with disabilities who have an individual educational plan or for whom an accommodation plan has been issued under Section 504 of the Rehabilitation Act of 1973. Gardiner Scholarships provide eligible students with the means to purchase services to design a customized educational program. These scholarships can be used for approved services such as speech or occupational therapy, instructional materials, tuition at an eligible private school, and contributions to a prepaid college account. Eligibility criteria include Florida residency, being eligible to enroll in kindergarten through grade 12 in a public school in Florida, and having a disability (including autism spectrum disorder, Down syndrome, and other disabilities as defined in Florida Statute 1002.385) (Florida Department of Education, n.d.).

In 2016, the Florida Governor signed into law the Florida Postsecondary Comprehensive Transition Program Act (FPCTP), which expands inclusive and experiential postsecondary education and employment for students with intellectual disabilities through degree, certificate, or non-degree programs. As a result, the Florida Center for Students with Unique Abilities was established at the University of Central Florida. There are more than 100 institutions of higher education throughout Florida, offering services and programs through the FPCTP to students with disabilities (Florida Center for Students with Unique Abilities, n.d.).

HOUSING

The shortage of affordable, safe housing has been a persistent issue in Florida. More than 35 years ago, the state Legislature created the Florida Housing Finance Corporation (also known as Florida Housing) to provide a range of affordable housing options and opportunities. Multifamily development includes incentives for the development of: rental housing, loans and mortgage bond programs, elderly housing community loans, low-income tax credits, and grants to serve persons with I/DD. The State Housing Initiatives Partnership (SHIP) makes funds available to local governments to form partnerships that preserve and create affordable homes and multifamily housing. SHIP dollars are distributed to all 67 counties and 52 community development block cities in Florida, where they are invested in housing assistance programs and policy and ordinance development. SHIP funds can fund emergency repairs, new construction, rehabilitation, fees, financing, matching dollars for federal housing programs, and homeownership counseling.

A confluence of factors drive the housing decisions of persons with I/DD and their families and caregivers. Housing affordability may be among the top factors individuals and families deal with. As reported earlier, almost 1 percent of Floridians live at or below the Federal Poverty Level and the incomes of persons with disabilities and without disabilities lag behind national figures (Demographics Table 22, Technical Appendix). Residents in rural Florida counties have higher rates of poverty than those in the 35 urban counties (Demographics Table 8, Technical Appendix). In Florida, more than 86 percent of persons with I/DD who live in individualized settings live in a family home (Demographics Table 15, Technical Appendix). In 2017, the average Supplemental Security Income (SSI) monthly payment for Floridians was \$773, which did not cover the average rent for a one-bedroom apartment, starting at \$850 (Housing Table 2, Technical Appendix); (Schaak, 2017).

A recent national study found that about 75.0 percent of adults with I/DD live with a parent or caregiver and are not connected to services and supports available through public programs. Five (5) factors ranked as the most important to persons with I/DD when deciding where to live included: safety, security and freedom from crime; cost; location; proximity to family; and quality of services and

supports. The dream home setting of 61.8 percent of study participants was their own home or apartment, followed by a supervised group home (14.4 percent) and home of family member or friend (11.9 percent) (Housing Table 9, Technical Appendix); (Friedman, 2019).

TRANSPORTATION

Created by the Florida Legislature in 1989, the Commission for the Transportation Disadvantaged develops policies and procedures for the coordination of transportation services the transportation disadvantaged. The Commission is assigned to the Florida Department of Transportation for administrative and fiscal accountability. Through the establishment of a planning agency for each service area and relationships with Community Transportation Coordinators (CTC), the Commission assures that local planning is aligned with its mission and that transportation disadvantaged riders receive services. Per Florida Statute 427.011, transportation disadvantaged funds may be used for: planning, Medicaid transportation, administration, operation, procurement and maintenance of vehicles, and capital investments. The statute stipulates that paratransit consists of those elements of public transit which provide service between specific origins and destinations as selected by the individual rider with service being provided at an agreed-upon time. Paratransit services can be provided by taxis, limousines, dial-a-ride services, buses, and other arrangements classified as demand-responsive with non-fixed route operations. Riders include older adults, persons with disabilities (physical or developmental), people with low income, and at-risk children. Chapter 427 Florida Statutes and Commission guidelines are used to determine rider eligibility, which must be established before services can be provided. The Americans with Disabilities Act (ADA) requires that public transit systems be accessible to individuals with disabilities. The ADA mandates that public transit entities that provide fixed-route rail or bus services also provide complementary paratransit services. However, individuals with disabilities must apply and be deemed eligible for paratransit services. The eligibility process is determined by the transit system as described above.

Statewide from 2017-2018, almost three (3) million trips were provided for persons with disabilities (Transportation Table 2, Technical Appendix). The highest percentage of unmet trip requests in Florida were related to employment and medical care. Unmet trip requests were higher in rural counties (Transportation Table 7, Technical Appendix).

CHILDCARE

Early care services, along with before- and after-school care services, are concerns for persons with I/DD and their families and caregivers. The U.S. Department of Health, and Human Services, Administration for Children and Families, Office of Child Care serves as a starting point in the search for

quality, affordable childcare for a child with a disability (HHS, Administration for Children and Families, Office of Child Care , n.d.). Florida has three Parent Training and Information Centers (PTI) and two Community Parent Resource Centers (CPRC) that provide information and support services. The Florida Department of Children and Families (DCF) regulates childcare providers and offers resources for choosing a child care provider (Florida Department of Children and Families, n.d.). The Florida Department of Education Office of Early Learning offers guidance and referrals for finding quality childcare. Through the Family Caregiver Support Program, the Florida Department of Elder Affairs provides child day care and/or sitter services for a child under 18 years of age with a disability living with a grandparent. The agency reports having provided 8,877 hours of day care services and 16,047 hours of sitter services for the Fiscal Year 2018-2019 (Services Table 4, Technical Appendix).

Families of children with disabilities face challenges with childcare, according to a 2020 study. More than one-third (34.0 percent) of parents of children with disabilities report having difficulty finding childcare, compared to 25.0 percent of parents of children with no disabilities. About 34 percent of parents of children with disabilities report not being able to find care, while 29.0 percent of parents of children with no disabilities report not finding care. Among the almost two-thirds (66.0 percent) of parents of children with disabilities who did find care, many had to rely on a patchwork of childcare comprised of paid care, family and friends covering care, and parents missing work. Relatedly, the parents of children with disabilities were found to be three (3) times more likely to experience job disruptions (e.g., arriving late, leaving abruptly or early, needing time off, and/or requesting schedule changes) because of childcare issues (Novoa, 2020).

RECREATION

As described earlier, in Florida, there is a variety of organizations that support and promote recreation services for persons with disabilities. These include the Florida Disabled Outdoors Association, Florida Special Olympics, and the Florida State Park Service, along with its national counterpart, the National Park Service, and local (county and city) parks and recreation agencies. Special Olympics Florida serves about 58,000 athletes and has more the 38,000 coaches and volunteers. They offer ongoing training and sports competitions in 11 fall and summer sports categories with a complement of additional competitions offered at various county and local levels. Special Olympics Florida brings their Unified Champion Schools education program to public schools and offers the Healthy Athletes program to Special Olympic athletes to improve and maintain fitness. Little ELITES (Elementary Level Introduction to Entry-level Sports) guides young athletes from ages 2 to 7 years into the Special Olympics program for those 8 years of age and older (Special Olympics Florida, n.d.).

The National Core Indicators (NCI) data provide some background on factors related to the recreational activities of adults with developmental disabilities in Florida.

TABLE 9. NATIONAL CORE INDICATORS (NCI) ADULT IN-PERSON SURVEY OF ADULTS WITH DEVELOPMENTAL DISABILITIES, RESULTS ON RECREATION-RELATED FACTORS, FLORIDA AND NCI AS A WHOLE, 2017

Recreation-related Factors	Florida	NCI as a Whole
Friendships	percent	
Has friends who are not staff or family members	81	78
Has best friend	76	70
Wants more help to meet or keep in contact with friends	39	42
Reasons Cannot See Friends		
Lack of transportation	47	38
Lack support staff	16	15
Rules or restrictions	14	10
Money or cost	17	10
Difficulty finding time	25	33
Community Inclusion		
Went out shopping at least once in the past month	91	89
Able to go out and do the things he/she likes to do in the community	84	85
Went out to eat at least once in the past month	89	86
Relationships		
Often feels lonely	8	10
Can go on a date or is married or living with a partner	78	75

Source: 2020 Technical Appendix, Recreation Table 1, 2020.

Public Input

Quantitative data from a vast array of secondary or administrative data sets in part describe the core issues and needs of persons with I/DD and their families and caregivers in Florida. The perspectives and opinions of self-advocates, their caregivers, providers, and agency leaders are essential to fully understanding the landscape and architecture of Florida's system of supports and services for persons with I/DD. For a diverse representation of Florida's population of persons with I/DD and those who care for them, the assessment sought public input through two phases of public input. WellFlorida Council worked with the Florida Developmental Disabilities Council to identify the types of public input (surveys, key informant interviews, and focus groups) and the populations of interest for each (Partners in Policymaking, Self-Advocates, Caregivers/Family Members, and Key Informants).

Phase I included the following:

- Focus Groups with Partners in Policymaking
- Self-Advocate Survey
- Caregiver/Family Member Survey
- Key Informant Interviews

Data collected for Phase I occurred from February 2020 – May 2020.

At the completion of the Phase I data collection, WellFlorida Council and the Florida Developmental Disabilities Council continued to receive public input through two additional focus groups with self-advocates and aging caregivers. These additional focus groups were utilized as a means to learn more about the issues facing self-advocates and aging caregivers. Issues related to aging caregivers was a topic of discussion among Council members, key informants, and Partners in Policymaking focus group participants which led to the facilitation of a focus group with aging caregivers. Furthermore, aging caregiver issues were relevant in secondary data findings. To better understand issues facing aging caregivers, WellFlorida Council and the Florida Developmental Disabilities Council facilitated a focus group with aging caregivers.

Phase II included the following:

- Focus Groups with Self-Advocates
- Focus Groups with Aging Caregivers

Data collected for Phase II occurred from June 15 – July 2020.

This section of the Comprehensive Review and Analysis shall follow the below outline:

- Focus Groups
 - Partners in Policymaking
 - Self-Advocates
 - Aging Caregivers
- Surveys
 - Self-Advocate Survey
 - Caregiver/Family Member Survey
- Key Informant Interviews

FOCUS GROUPS

FOCUS GROUP WITH PARTNERS IN POLICYMAKING

Methodology

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to develop a focus group script used with advocates from Partners in Policymaking. The focus group script can be found in the Appendix. Advocates from Partners in Policymaking are mostly parents or caregivers of school-aged persons with I/DD. The focus group script was comprised of eleven (11) questions regarding: Advocacy and Partners in Policymaking; Perceptions of the biggest issues facing persons with I/DD and their families in Florida; Perceptions of biggest issues facing caregivers and family members of persons with I/DD in Florida; and Special Populations. Two in-person focus groups were facilitated with Partners in Policymaking advocates with 10 – 11 advocates in each group. Each focus group was facilitated by trained focus group facilitators utilizing the approved focus group script. Focus groups lasted approximately 1 hour, 45 minutes and were held in Tallahassee on Monday, February 10, 2020. Focus groups were audio recorded with permission, and the audio recordings were transcribed verbatim for analysis using a qualitative data software, MaxQDA.

Using MaxQDA, the transcripts were analyzed and themes were identified. Themes are topics that were mentioned multiple times by multiple focus group participants. In total, over 420 sections of text were coded into one or multiple themes and twenty (20) themes were identified. The table below outlines the focus group themes and their meaning.

TABLE 10. PARTNERS IN POLICYMAKING FOCUS GROUP THEMES AND MEANING SUMMARY, FEBRUARY 2020

Coded Themes	Theme Meaning/Summary
Lack of knowledge and information	Information about services is difficult to find; many people are not aware of the services available or how to receive them. Access to information is often gained through a support coordinator or other provider, therefore, the quality and knowledge base of providers can hinder or assist in caregiver awareness and access to services. Finding resources can be very challenging for parents new to I/DD in Florida. Individuals with language barriers likely experience increased challenges related to finding information.
Access to services	Any discussion of access to services
Special Populations	Populations who are underserved or unserved or who experience additional barriers. These special populations included: those with limited English proficiency and those persons living in areas with limited services in close proximity to their residence.
State System	Medicaid, Waiver, iBudget, state sponsored programs
Providers	Any discussion of providers (medical, dental, social, behavioral)
Abuse and Neglect	Restraint and seclusion, physical and emotional abuse, misunderstandings with police unaware of I/DD diagnosis and maladaptive behaviors/mental health diagnosis/dual diagnosis
Funding	Government sponsored programs
Employment	Employment and training opportunities for persons with I/DD. Employment barriers for persons with I/DD. Impacts of caring for someone with I/DD on employment.

Coded Themes	Theme Meaning/Summary
Biggest Need for persons with I/DD and their families	Responses to a scripted question related to biggest need for persons with I/DD and their families
Advocacy Aims	What participants advocate for
Recommended Changes to PIP	Ways to improve the Partners in Policymaking Program
Positive Aspects of PIP	Knowledge learned through PIP, aspects of the program that helped advocates, benefits of being in Partners in Policymaking
School/Education	Any discussion of school or education including early education, primary education, and secondary education
Biggest Personal Challenges as an Advocate	Responses to a scripted question related to their biggest personal challenge as an advocate
Barriers	Reasons why they are unable to get the services they need for the person with I/DD or for their families.
Caregiver Issues/Family Impacts	Unique challenges faced by caregivers and family members of a person with I/DD
Insurance	iBudget, insurance, Medicaid, Waiver, insurance as a barrier, etc.
Medicaid Waiver	iBudget, Waitlist, Medicaid
Advocacy Definition	Responses to a scripted question related to the definition of advocacy
Waiting List	iBudget, Waiver, health, behavioral, dental, community support services waitlists, not accepting new patients/clients

A word cloud is a visual representation of the words most often spoken during a focus group or recorded discussion. Below, is a word cloud from the PIP focus groups. The largest and most bold words in the word cloud were spoken most frequently. The following words were the most spoken:

- Need

- Services
- Advocate
- Help
- Support
- School
- Kids

PIP advocates expressed *needs* for *services* and supports both in *school* and out of school for their *kids*. They generally spoke about *needing help* finding and getting *services* from *high quality providers*.

FIGURE 16. WORD CLOUD PIP FOCUS GROUPS, FEBRUARY 2020



The *Response Summary* section that follows presents each of the focus group questions and catalogs, through paraphrasing and via bulleted lists, the key, and most frequently occurring responses for each question.

Advocacy and Partners and Policymaking

Question 1: What does the term “advocacy” or “self-advocacy” mean to you?

- Standing up for what’s right and deserved
- Defending people’s rights
- Support bills that are important to our families
- Provide moral and emotional support
- Taking action

- Empowerment is the goal of advocacy
- Change
- Equality for those with I/DD
- Being heard, having the courage to speak up
- Determination
- Self-advocacy
- Standing up for oneself
- Defending my rights, it's a process to move from advocacy to self-advocacy
- Passing the torch to be a better self-advocate
- Fighting for your rights, not necessarily an adversarial fight, and begins with being informed

Question 1B: What are you advocating for?

- Rights and needs of our daughter
- Information
- Transparency of the system as a whole and all it encompasses
- Recreation
- Elimination of language barriers for those whose first language is not English or who are non-English speakers
- Children in the foster care system with I/DD
- Awareness
- To change disparities in access to services and supports
- Transfer of tools/information/knowledge to future parents of children with I/DD
- Access according to needs and things/services that are not in place
- Florida is underserved, more needs to be done
- Caregiver pay
- Waitlist
- Shortage of funding
- Services and treatments to achieve the life goals of people with DD
- Inclusion in education
- Trained teachers who are prepared to work with children
- Information and therapies we're entitled to
- Helping other parents not to lose (or waste) time

- Filling the service gaps for children 0-5 years of age in the critical years of development, and lost time in child development
- Because the timing of investments is off, children have severe deficits later when in school and in a career.
- Parents to help each other
- A system that does not bank on parents not knowing what they should get and makes them afraid of retribution by teachers and administrators
- Failures in reading skills need to be fixed
- Focus on use of restraints, cameras in classrooms, elopement, use of Baker Act, and drowning and injury prevention
- Vocational rehabilitation for all students and adults as well

Question 2: What is the biggest personal challenge you have in being an advocate or a self-advocate?

- Lack of knowledge in regard to I/DD system and legislative system
- Time, managing all that needs to be done
- Inability to communicate and need for a caregiver (specially referring to self-advocate)
- Time to fight
- Exhausted in general, not enough hours in the day to spend on extracurricular activities like advocacy
- Legality of right to services and general awareness as to what individuals with I/DD are entitled to receive
- Money, costs (x2)
- Need to travel to get services
- Transportation
- Access to information and understanding what's available
- Always being told "no"
- Changes made in my child's plan without my knowledge, which may be (happen) more so in minority population
- Added burdens and pressures to families

Question 3: How did Partners in Policymaking help you learn to be a better advocate or self-advocate?

- Giving us access to information, for example, on rights and services
- Put things into perspective and the ability to work on issues that are most important as a group

- Motivation and empowerment
- Being among likeminded people
- Networking, being around other self-advocates and advocates with a larger purpose
- Have tools we didn't have before
- Being with peers
- Affiliation with PIP gets people's attention
- Hearing about the experiences of other parents and learning about their successes
- Learned to empower, not protect
- Videos
- Opened my eyes to others' issues and system-wide issues

Question 4: What else can the Council do to help you effectively advocate or self-advocate once Partners in Policymaking training is over?

- More training, in-depth training
- Funding for training must be provided
- Doesn't have to be in-person training, could be with use of technology
- Continuing education (e.g., follow Florida Master Naturalist program model)
- Discussion groups on-line, and on-line discussion groups as part of training
- Parent groups
- More information on existing self-advocacy groups
- Linkage to previous PIP alumni and classes
 - by geography to link with other PIP grads in region
 - alumni list by county
- Create a technology platform that everyone be part of
- Share previous PIP projects, let us build on previous projects
- Make an effort not to treat all individuals with I/DD and their families as the same because not all families are the same
- Treat those with more complex children differently because the needs are not the same
- Reduce the amount of paper information and use a digital format
- Leeway of accepting absences due to family emergencies
- Record webinars or archive information so it can be accessed in the future after graduation
- Focus on general, broad topics

- Too much focus on autism
- Should implement regional meetings to continue advocacy efforts after PIP
- Hold an annual, statewide alumni meeting
- Increase the number of self-advocates in the program
- More support for self-advocates is needed

Perception on Biggest Issues:

Question 5: What is the biggest issue for persons with I/DD in Florida?

- Waiting list, APD not being clear about when and if an application is needed
- Funding
- Access to services
- Lack of understanding by the general public, school system, etc. People with DD are judged and looked down upon
- Inclusion hasn't been reached
- Implementation of ideas in the school system doesn't always happen, and it is throughout the school career
- Written plans may be beautiful, but they don't get implemented
- Accountability (related to schools and plan implementation)
- No system change, no leadership at DOE
- Starting young with interventions so that we're not trying to correct issues that surface in teens and young adulthood
- Top-down problems (leadership)
- Low wages for caregivers, leads to poor quality care
- Ability to pay for services is difficult without being on the waiver
- General provision of services is lacking
- Lack of consistency of services
- Quality of one provider may be different than another
- Stockpiling supplies due to uncertainty of next delivery or if the supplies will be covered by insurance in the future
- Lack of employment for persons with I/DD
- Abuse and neglect
- Persons with I/DD are more likely to be abused

- Lack of training for law enforcement when dealing with someone with I/DD. The person with I/DD may have maladaptive behaviors, a dual diagnosis, mental illness.

Question 6: What is the biggest issue for family members or caregivers?

- Burnout
- Fatigue
- Worry about the future
- Financial impact of not being able to work because of the lack of services, which creates a cycle that never ends
- Services for siblings, need support groups of peers and people who understand the situation siblings face
- Social support for parents is limited due to inability to socialize because of the needs of the child with I/DD
- Personal safety and happiness of families, having a purpose in life
- Need to be among other parents to share tears, feel safety among those who understand, not feel isolated
- The more problems your child has, the more isolated and cut-off you become, you feel less welcome and invited
- Costs, many out-of-pocket expenses
- Lack of knowledge about services. Information seems “secretive”
- Too much emphasis on family’s total income
- Access is limited because family does not meet FPL to qualify for Medicaid, but cannot afford all the services needed for the child on their own.
- Lack of awareness on behalf of providers/Quality of providers

Question 7: What do you think about the services for self-advocates and their families in Florida?

- Florida is the worst of the worst for services
- I’d tell people to run from Florida if they can
- Services are lacking
- You might be able to find good services, but you will have to pay out of pocket for them
- Florida university system doesn’t support careers for professionals to care for people with DD
- Wages for support service providers are so low it results in poor quality of workers and care
- Money follows the priorities, we’re not a priority

- Florida needs inclusion as norm, in everything—school, work, community
- Persons with DD are viewed as separate

Special Populations:

Question 8: Are there persons with I/DD in Florida, or groups of persons with I/DD (e.g., non-English speaking people) who do not get the services they need? Who are they?

- Low socio-economic groups, people who live in underfunded school districts
- Those who have economic means can get more services
- Money is the great divider, even if they advocate for others, it doesn't translate to the larger system
- Those with limited English proficiency
- Class divisions are always there
- People with language barriers (example of child translating for parent, not understanding the problem and nor what's available to them)
- Rural families, services not available in their areas, transportation not available, group homes may be far away from their family home
- All persons with I/DD are excluded
- Gifted autistic students; don't participate in services because of behaviors, school system doesn't know what to do with them, kids end up getting pushed through and out of the system
- Relatedly, gifted students are not exposed to persons with DD
- Those with low behavior management support, it permeates throughout their education

Question 9: Does race, ethnicity, or sexual orientation of persons with I/DD in Florida influence their ability to get the services they need? How?

- These prejudices are found in all, including towards persons with DD
- The disability is seen first, then judged on other aspects (race, gender, ethnicity)
- Language barriers, not being heard, are more the barriers
- More transgressions are experienced because of race
- Would be on a case-by-case basis with providers
- For Whites, DD is more likely to be treated as behavior problem. With minorities, there is more law enforcement involvement.
- Use of restraints and seclusion is a big fear

Question 10: For those of you living in rural areas of Florida, do you experience barriers getting services due to your location? If so, what barriers do you experience and why?

- Providers don't have staff, long waits
 - this is true even in cities, not just rural locations
- No providers
- No transportation
- Lack of awareness of where you can get services
- Section 8 housing is far out, further segregating the self-advocate
- No group homes
- Requires a lot of energy and work to get services in rural areas
- Have issues attracting providers, low pay

Question 11: What are your thoughts and experiences regarding specifically the Medicaid waiver and the process of applying for and qualifying for it?

Note: not all participants had experience with the Medicaid waiver

- Fantastic experience and recently was given an increase in spending on the iBudget waiver
- Bryan's case shows a positive outcome with the waiver
- Found out there was an application for the application or a waiting list for the waiting list
- Not clear if you get on the list at 3 years or 5 years
- Didn't understand how it works
- Didn't know my rights
- Packet is difficult to complete and takes hours to fill out
- Challenge to apply for those who aren't as educated (example of elderly parents applying for adult child)
- Districts require different documentation
- Once on the waiting list, you don't hear anything
- APD helped parents get their kids on the waiting list but then lost the paperwork
- APD wants people to get on the waiting list (x 2)
- Florida needs to know how many people need help
- Recognize how large the problem is
- When moving to another state, must start over

Partners in Policymaking Key Themes:

While the focus group script was comprised of 11 questions, these questions can be comprised into two (2) main thematic need-based perceptions:

- Perceptions of the biggest issues facing persons with I/DD
- Perceptions of the biggest issues facing caregivers and family members of persons with I/DD in Florida

Each focus group was thoroughly analyzed and themes (those ideas, concepts and perspectives most frequently mentioned) identified. Once identified, these overarching themes for each domain were catalogued for each of the two thematic domains. Each of the two thematic domains and the overarching themes for each are provided below.

Biggest Issues for Persons with I/DD

- Lack of funding for needed services
- Low funding for caregiver services leading to low quality service provision or inability to find a service provider
- Lack of local service providers for needed services
- Threats to iBudget Waiver, Including Waitlists
- Lack of knowledge and understanding of the I/DD system
- Unaware of rights
- Employment barriers
- Challenges in the public education system in accessing educational and therapy services
- Transition Assistance throughout Life Stages
- Aging of Persons with I/DD and Aging of their Family Members and Caregivers who Provide Support
- Restraint and seclusion a fear, especially for persons with dual diagnosis or maladaptive behaviors related to their I/DD

Biggest Issues of Families and Caregivers of Persons with I/DD

- Transportation
- Accessing quality services for their loved one
- Maintaining employment difficult due to various needs of person with I/DD not met by outside entity or provider, especially if not receiving iBudget
- Caregiver Fatigue and Burnout
- Financial burden related to unallowable costs, insurance coverage, added therapies and copays

- Knowledge of Services and How and When to Access
- Lack of social support due to inability to fully participate in society and social networks due to limitations of the person with I/DD, feeling ostracized by society at large
- Fear of mistreatment by police especially for those with maladaptive behaviors with I/DD
- Aging Family Members and Caregivers who Eventually Cannot Provide Support or Need More Caregiving Support (in Some Cases) than Their Loved Ones with I/DD

FOCUS GROUPS WITH SELF-ADVOCATES

Methodology

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to develop a focus group script for use with self-advocates. The focus group script can be found in the Appendix. Due to the rise of the coronavirus pandemic, the focus group was facilitated virtually using Zoom. The focus group was facilitated by trained facilitators on June 26, 2020 for a duration of two hours. Seven self-advocates participated in the focus group. The purpose of the focus group was to: Identify the biggest issues for persons with I/DD and their families; Understand the impact of support received from caregivers/family; Understand their experiences with the I/DD system; and Identify needed services and improvements to the I/DD system. The focus group was audio recorded and were transcribed verbatim for analysis.

Using MaxQDA, the transcripts were analyzed and themes were identified. Themes are topics that were mentioned multiple times by multiple focus group participants. In total, over 100 sections of text were coded into one or multiple themes and nine (9) themes were identified. The table below outlines the focus group themes and their meaning.

TABLE 11. SELF-ADVOCATES FOCUS GROUP THEMES AND MEANING SUMMARY, JUNE 2020

Coded Themes	Theme Meaning/Summary
Transition from Childhood to Adulthood	Responses to a scripted question: What was your experience with the Florida I/DD service system when you transitioned from childhood to adulthood?
Healthcare	All comments related to healthcare, including barriers and challenges to accessing care, accessibility of service locations, etc.
Medicaid Waiver	iBudget, Waitlist, Medicaid

Coded Themes	Theme Meaning/Summary
Self-Directed Care	Self-advocates desire to participate in decisions related to their care. To the extent possible, all persons with I/DD can participate in self-directed care.
Design Service System	Responses to a scripted question: If you could design a service system for people living with your type of disability, what would it look like?
Aging Caregiver	Concerns related to aging caregivers, typically a parent or family-member who provides support (physical and/or financial). Who will provide these services when aging caregivers are unable to provide them?
Support Received from Others	Responses to a scripted question: What kinds of help do you currently have from others? Who are they?
Most Important Issues	Responses to a scripted question: What are the most important issues you believe self-advocates living with an intellectual or developmental disability are facing today?

A word cloud is a visual representation of the words most often spoken during a focus group or discussion. Below is a word cloud generated from the self-advocate focus group. The largest words and those in bolder font were spoken most frequently. The following words were the most spoken:

- Need
- Services
- Support
- Help
- Medicaid
- School
- Waiver

FIGURE 17. WORD CLOUD OF SELF-ADVOCATE FOCUS GROUP DISCUSSION, JUNE 2020



The *Response Summary* section that follows presents each of the focus group questions and catalogs, through paraphrasing and via bulleted lists, the key, and most frequently occurring responses for each question.

Question 1: What are the most important issues you believe the self-advocates living with an intellectual or developmental disability are facing today?

- Health care and health insurance
- Lack of expanded Medicaid
- iBudget Waiver Waitlist (x7) and concerns of losing coverage or receiving fewer benefits
- Transitioning from one state to another is difficult; benefits are state-based and do not follow people from one state to the next
- Lack of physical accessibility and consideration in healthcare facilities; facility required me to bring a person to help me transfer, but due to COVID, would not allow that person inside. Lack of effective communication at facility.
- Transportation barriers
- Inability to keep Medicaid and be employed (x4)
- Service systems do not communicate with one another. Must call multiple people and agencies to find help and no one has answers. Lack of interconnectedness among agencies and systems
- Navigating the system is exhausting, people give up.

- Lack of support to help self-advocates and their families understand the system and understand how to navigate the system to get the services needed regardless of insurance or iBudget Waiver

Question 2: What is the biggest issue you are facing today?

- Lack of services
- Transportation (x3)
- Getting community support services
- Safety related to transportation (can be problems with the Medicaid bus)
- Must be in crisis-mode to get help, so people have learned how to trick the system to get off the waitlist.
- Being on the Waitlist and not knowing when that will change or how to get services
- APD website is not consumer friendly. Difficult to help parents through the system
- Healthcare and housing. Housing is about affordability, but also accessible housing is important. Finding affordable housing that is also accessible is challenging.
- Navigating the system, understanding how it works and how to get services (x3)
- Bureaucracies that do not interact lock individuals and families out of systems
- People do not know what they do not know, so they cannot get the services they do not know exist. They do not know where to start looking.
- Affordability of services

Question 3: What kind of help do you currently have from others and who are they?

- Help From:
 - Job coach
 - Advisor
 - Church
 - Friend paid through CDC+ who provides personal care assistance
 - Family (x6)
 - ARK Village staff
 - Florida SANS
 - Vocational Rehab
- Help With:
 - Financial support from family

- Financial support from CDC+ that pays for personal care assistant
- Personal care assistant helps with physical needs, cooking, cleaning, etc.
- Cleaning and cooking
- Transportation
- Participating in community activities
- Emotional support

Question 4: If you have a caregiver who helps you with physical or financial needs, what would happen to you if that caregiver was no longer able to help you?

- “Without Mom it would be difficult. I don’t have any real good assets.”
- When I die, I don’t know who will help my son
- “Without help from the ARK Village, people would live on the streets.”
- The ARK Village is working on a guardianship package to help families prepare rather than dropping special needs language on someone who doesn’t understand the language and system. “A targeted case manager would help.”
- “If I didn’t have a caregiver when I was in Panama City during the hurricane, I would not be here.”
- Without the support of my parents, I would be in a group home. “I don’t want to be in a group home.”
- I would be in a safety-net situation
- I would end up in an ICF or worse – dead
- Group home

Question 5: What changes to the level of support you receive would impact your ability to live independently?

- I have supports through my family, they are my major source of support. There is a long need for assistance with planning as people age. Our mother is 70 years old and she is the primary caregiver. She will not live forever. There needs to be more money to discuss and address that issue.
- Planning is an ongoing process because health care needs evolve. There needs to be a long-term assistance to help people plan. The current system is setting up people to be in a crisis situation when support assistance changes.
- “If you don’t have a support coach, your apartment will look nasty.”
- Supportive living coaches make \$11 an hour, “they have to flee to different jobs.”
- “I depend on support. I have a lot of friends who support me. They want to help me.”

- “We need our services. I have asked for more services from APD, as I get older my needs increase. It is really hard because I was not able to use all the hours I needed because I couldn’t find people to work them, then switched to CDC+. So, my services make me independent, but they make me too independent to get more services. Using CDC+ this self-advocate can pay more for personal care assistants than she was able using iBudget Waiver, non CDC+.
- Without my support I would not be able to work
- Without family, would lose companionship and vacations and trips and experiences

Question 6: What was your experience with the Florida I/DD system when you transitioned from childhood to adulthood? Were you able to find and get the services you needed? If not, what services did you need that you didn’t get?

- Must start planning for transition early
- There was no financial motive for anyone to help me. Having a dual diagnosis opened doors, but I didn’t know that.
- In school, I got services, but it was important to get the ball rolling for services when I graduated.
- Going away for college was difficult. People didn’t want me to do it because it would require more supports than living at home.
- Finding appropriate medical care was difficult and having a doctor that understood my needs was difficult.
- It was easy for authority figures to push me to a path they saw for me, but because I had the support of family I was able to self-direct my path.
- My transition out of high school wasn’t good. High school wasn’t good either. There was no transition. I worked for Goodwill for \$.18 an hour, then when I got a real job the counselors came to my job, it wasn’t good.
- I had more services in high school, now “I don’t get physical or occupational therapy.”

Question 7: If you could design a service system for people living with your type of disability, what would it look like? What new services would be included? What current services would be included? Which service providers or professionals would be needed?

- Eligibility would be expanded.
- Everyone would have a case manager. You could find out what services you needed and what you are eligible for. Assurances of continuity if case manager changes.
- Case managers who understand the whole system
- More education requirements and training for case managers

- I am a benefits planner, it is hard to know everything. If you had someone to tell you the basics of each place offering services that would be a good service to have. We need more education and training for providers and we need more pay for those providers. Working should not impact our ability to get Medicaid.
- The ARC in Jacksonville has an advocacy department that is a resource for families. We need more places like the ARC, it is a great community. We need communities with roll-in showers, it is a choice to live here. We need to separate stigma and build more places like this one. Use the ARC of Jacksonville as a model.
- I would like to see a system of persons with disabilities being guided by their peers (persons with disabilities) so people can share their experiences. A system needs to allow persons to be as autonomous or involved as they want. Making sure individuals get their needs met and the things that are appropriate for the needs.
- Less stigma regarding where people live (ICF)
- We need a system that is evolving and has an evaluation process. You may go years without needing anything, but then you may need a lot as you age.
- Interagency communication and connectedness. The services within the system should communicate with each other and the individual being served.
- System that knows the needs and knows if those needs have been met.
- No more “about us without us”

Question 8: What has your experience been with the Medicaid Waiver? What has been your experience when you try to change or add services?

- “Medicaid Waiver needs to improve on a big scheme.”
- Medicaid is not adequate.
- “I’ve been on it for a long time. If I got off, I would lose all of my services.”
- There is underutilization of CDC+ option which could help people use better supports.
- There should be a certification process for Care Coordinators.
- Need service providers who are male who can help with personal care, especially on the weekend and off-hours. Especially if you only need a few hours. Service providers should be trained on how to provide services. Feels like they get anyone off the street to provide the services – it can be dangerous.
- Billing problems and financial burdens you did not know where coming
- Language barriers

Question 9: If the Florida Developmental Disabilities Council had to pick one thing to change, what should it be?

- Expanded Medicaid. That is important to everyone with a disability (x2)
- Fully fund the Waitlist
- Get rid of documentation requirements
- Clarify definition of “crisis” for the waitlist

Self-Advocate Focus Group Key Themes:

While the focus group script was comprised of eight (8) questions, these questions can be comprised into four (4) main domains:

- Biggest issues self-advocates experience
- Impact of support received from caregivers/family
- Experiences with the I/DD System
- Recommendations for Improvements to I/DD system

Each of the four domains and the overarching themes for each are provided below.

Biggest Issues Self-Advocates Experience

- Transportation barriers
- Housing – lack of affordable, safe, accessible options
- Employment – difficult to work and keep state-sponsored benefits (Medicaid)
- Complicated and Challenging I/DD system:
 - Difficult to navigate the different systems
 - There are many providers and agencies involved, but there is a lack of interagency communication and
- Healthcare and personal care related issues:
 - Lack of Medicaid expansion
 - iBudget Waiver concerns including losing coverage or receiving less coverage
 - Being on the Waitlist with an unknown end date

Impact of Support Received from Caregivers/Family

- Support Received from Caregivers/Family
 - Help with physical needs including personal care, cooking and cleaning, shopping, etc.
 - Financial assistance

- Transportation
- Companionship
- Recreational opportunities
- Impact of Support Received
 - Ability to live in an apartment or family home instead of a facility
 - Access to services and employment via transportation provided
 - Personal safety
- Impact if Caregiver/Family Member Support Ended
 - Risk to safety and well-being
 - Lack of financial resources
 - Lack of emotional support and companionship
 - Lack of support navigating the I/DD system
 - Lack of transportation to employment and services
 - Caregivers/Family member support integral to the daily well-being of self-advocates. Without this support, self-advocates would need increased level of services from safety-net providers and the I/DD system. Loss of such supports would create a crisis situation for self-advocates.

Experiences with the I/DD System

- Difficult to navigate the disjointed system
- Lack of interagency communication within the system
- Self-advocates and advocates must call multiple places and people for help or answers and sometimes it is too complicated to find answers or resolutions
- Extremely difficult system to navigate for those who are new to I/DD or unfamiliar with the systems
- Medicaid is inadequate. Unable to get services that are needed. Difficult to find providers willing to accept low rates. Difficult to receive an increase in Medicaid Waiver services when needs change
- Without Medicaid Waiver, many people cannot access services. There is no statewide safety-net for them.

Recommendations for Improvements to the I/DD System

- Improve interagency communication
- Improve I/DD System's ability to respond to the changing needs of self-advocates
- Ensure all case managers are well-trained and familiar with available resources. Ensure continuity of care for self-advocates even if their case manager changes
- More education and training for care coordinators

- Increased pay for providers
- Expand Medicaid, remove people off the waitlist
- Evaluate of the system
- Peers helping peers navigate the system
- Ability for self-advocates to work without risk of losing benefits

FOCUS GROUPS WITH AGING CAREGIVERS

Methodology

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to develop a focus group script for use with aging caregivers. The focus group script can be found in the Appendix. Due to the rise of the coronavirus pandemic, the focus group was facilitated virtually using Zoom. The focus group was facilitated by trained facilitators on June 25, 2020 for a duration of two hours. Nine aging caregivers, defined as 60 years or older, participated in the focus group. The purpose of the focus group was to: Identify most important issues facing aging caregivers; Understand the daily and weekly role of caregivers; learn recommendations for improvements for the I/DD service system; and Understand aging caregivers' long-term plan for person with I/DD in their care. The focus group was audio recorded and were transcribed verbatim for analysis.

Using MaxQDA, the transcripts were analyzed and themes were identified. Themes are topics that were mentioned multiple times by multiple focus group participants. In total, over 100 sections of text were coded into one or multiple themes and five (5) themes were identified with thirteen (13) subthemes. The table below outlines the focus group themes and their meaning.

TABLE 12. AGING CAREGIVER FOCUS GROUP THEMES AND MEANING SUMMARY, JUNE 2020

Coded Themes (Subthemes)	Theme Meaning/Summary
Most Important Issues for Persons with I/DD	Responses to a scripted question: "What are the most important issues facing older caregivers of aging adults with I/DD today?"
(System Challenges)	Difficulty experienced trying to access the I/DD system
(Abuse and Neglect)	Fear of what will happen to the person with I/DD in their care if they are not able to care for them. Worry of mistreatment (abuse and

Coded Themes (Subthemes)	Theme Meaning/Summary
	neglect) of service providers, lack of service providers, etc.
(Caregiver Stress and Fatigue)	Caregivers do not have a break from the stress of caregiving. Even with support and personal care or respite care, caregivers/parents must always be ready to answer questions or respond to a crisis.
(Time on Waitlist)	Unsure how long child/dependent will be on the waitlist. Lack of supports while on waitlist.
(Support Care Challenges)	Difficult to find support care due to the pay rates of support care workers, quality and training of support care workers is also a challenge.
(Transportation)	The Medicaid bus is a bad option, so transportation for work, medical appointments, etc. falls on caregivers
Housing	All comments related to housing for persons with I/DD
Medicaid Waiver Process Challenges	Challenges related to the waitlist
Long-Term Care Plan Challenges	Refers to the plans aging caregivers have made or not made for their children with I/DD. Varies on resources and those without financial resources worry what will happen to their children when they are not longer able to care for them.
Opportunities for Improvement	
(Support Care)	Need for more support care, better training for support care workers
(Medicaid Waiver)	All discussions related to improving the Medicaid Waiver including the waitlist
(Lack of Funding)	All discussions related to lack of funding for needed services and supports
(Housing Alternatives)	Long-term supported housing solutions for those with I/DD

Coded Themes (Subthemes)	Theme Meaning/Summary
(Lack of Data on Providers)	Inability to find providers, lack of trained providers, unsure of quality of providers. No system to monitor and track providers
(Training of Providers)	Need to increased training for providers, support providers, care coordinators, etc.
(Quality of Providers)	Concerns related to the quality of providers

A word cloud was generated from the aging caregiver focus group discussion. The largest words and those in bolder font were spoken most frequently. The following words were the most spoken:

- Services
- Need
- Support
- Aging
- APD (Agency for Persons with Disabilities)
- Caregiver
- Can't
- Developmental
- Disabled
- Families
- Funding
- Help

FIGURE 18. WORD CLOUD OF AGING CAREGIVER FOCUS GROUP DISCUSSION, JUNE 2020



Question 1: What are the most important issues facing older caregivers of aging adults with I/DD today?

- Not enough service/care provided by care coordinators (need more hours)
- Safety issues for both the caregiver and the self-advocate
- Safety from abuse and neglect
- Accidental injury (falls, burns)
- Medication errors or failure to take meds
- Added concern when family member cannot verbalize or express themselves
- Confidence in the quality and level of caregiving being provided to family member with I/DD
- Declining personal health with aging
- Always having to be “on” or ready to jump in when something happens to family member
- Lack of support groups
- Lack of information, particularly printed materials, about services and resources

Question 2: What are the most significant worries you and your family have?

- All issues described above
- Injuries to caregiver and family members

- Assurance that the legal documents and plans we put in place will be executed according to the family's wishes.

Question 3: What kinds of help do you currently provide to your family member with a disability on a daily basis? What kinds of help do you provide to your family member with a disability on a weekly basis? (Prompt for types of oversight/supervision provided for a family member living outside the home)

- Daily:
 - Everything, all activities of daily living (feeding, bathing, personal hygiene, transporting to services, etc)
 - When living in separate place, still have to provide emotional support and make multiple phone calls to remind them of things
 - Make up to 10 calls a day to check in
 - Feel the need to apologize for being grouchy at times when family member needs emotional support
- A few self-advocates have returned to the family home during COVID-19 pandemic. There are concerns about the readjustment when they return to their previous living arrangements
- Weekly:
 - Transportation to job

Question 4: If you could design a service system for families like your own, what would it look like? What new services would be included? What current services would be included? What service providers or professionals would be needed?

- On-site assistance for those who live independently
 - Help with household tasks and upkeep
- Support care coordinators who are well-trained and professional; not just babysitters
- Better interagency coordination (DOEA and APD duplicate or very nearly provide the same service, these services could be done more effectively and efficiently by one agency.)
- Expanded options for congregate living that accommodate needs of aging caregiver and their family member together
- Continuity of care when people move from place to place, including from other states. The same level of care should be provided everywhere.
- A way to keep people from falling through the cracks and provide services to everyone who needs them

Question 5: Have you thought about what will happen to your loved one when you are no longer able to provide care? Do you have a long-range plan for care of your loved one? For yourself? What advice would you give to other older parents?

- Disabled and Alone Service – contracted service to assure the documentation is in place to care for family member when caregiver is no longer able to. It requires a financial investment
- Legal services are expensive, so we don't use them even though we know they are needed
- Not sure what to do. Family members have their own issues. Unsure who will help when I am unable
- Need data on the financial consequences of having to care for a family member. Data on how investments in early care could have benefits and savings in the long-run.
- FDCC's 'Planning Ahead' materials are helpful for families who are trying to plan ahead
- A new residential option (all participants agreed)
 - Something between a group home and ICF
 - A combination of supported living and ICF, but not isolated
 - A place where a person can maintain their dignity while getting a little more care
 - Similar to what we would all want in an assisted living facility for persons without I/DD

Question 6: How would you rate the current service system in Florida? Use a 1 – 5 scale, where 5 is the best and 1 is the worst. What aspects could be improved?

- Scores were an average of 1.67
 - 1 (x3)
 - 2 (x2)
 - 3 (x1)
- What aspects would be improved?
 - Convolutioned system
 - Need ranking system or way of scoring services, or recommendations for good service providers
 - Services fall short year after year
 - Abuse and neglect are grave concerns; abuse and neglect might be insidious or incremental when support care coordinators/providers get complacent
 - More rigorous provider training and oversight of that training and maintaining standards

Question 7: What do you think about the Medicaid Waiver and the process of applying for and qualifying for it?

- Waitlist is unacceptable
- One person's family member waited 16 years; another waited 15 years
- One person's family member "fell into getting services" by coincidence of timing with change due to APD being sued
- Politics of funding for Medicaid waiver are shameful
- APD doesn't explain clearly how to qualify
- Agency culture in the in-take section is one of "we don't have enough resources and we can't help you"
- Diversion options are not provided
- Every person on the waitlist is eligible and entitled to ICF/DD services
- Florida is not building any additional ICF/DDs

Question 8: If the Florida Developmental Disabilities Council could focus on changing only one thing to help older caregiver of individuals with I/DD, what would it be?

- Stop budget cuts
- Assurance that funding will be maintained at a certain level; can't plan when there is a threat of cuts every budget cycle
- Advocate for shared funding and services with DOEA
- Take advantage of the revenue sharing component of the Florida iBudget waiver from APD

Aging Caregivers Key Themes:

While the focus group script was comprised of eight (8) questions, these questions can be comprised into three (3) main thematic need-based perceptions:

- Most Important Issues for Aging Caregivers
- Long-Term Care Plans
- Improvement Recommendations for the I/DD System

Each focus group was thoroughly analyzed and themes (those ideas, concepts and perspectives most frequently mentioned) identified. Once identified, these themes for each domain were catalogued for each of the three thematic domains.

Most Important Issues for Aging Caregivers

- Lack of funding for needed services
- Low funding for provider services (personal care assistants, etc.) is leading to low quality service provision or inability to find a service provider willing to accept low rates
- Concerns related to the quality of service provided by caregivers (service providers)
- Lack of local service providers for needed services
- Threats to iBudget Waiver, Including Waitlists
- Lack of knowledge and understanding of the I/DD system, unable to know what services are available and how to access those services
- Caregiver burnout and continual stress related to being the primary parent/caregiver for a person with I/DD. This stress and burnout are not relieved by respite care or in-home assistance because when there is a problem or an emergency, the primary parent/caregiver is needed. Caregivers are always “on”
- Lack of support for caregivers
- Concern related to personal health due to aging and lack of certainty related to who will take care of person with I/DD when aging caregiver is no longer able to serve in that capacity
- Without financial resources, it is difficult to prepare for long-term care of person with I/DD
- Concerned with possible abuse and neglect of person with I/DD, especially if that person is unable to communicate or has a dual diagnosis or maladaptive behaviors
- Concerned about personal safety and safety of person with I/DD due to maladaptive behaviors

Long-Term Care Plans

- Lack of long-term planning due to limited financial resources. Long-term care planning is expensive and requires financial resources. Many aging caregivers do not have access to those resources
 - Caregivers with long-term care plans worry those plans will not be followed, even though legal documents have been developed. Fear that the person with I/DD will no longer have an advocate working on his/her behalf when the aging caregiver passes away or is no longer able to serve as the primary caregiver.
- Difficult to find another person willing to be the primary caregiver for person with I/DD
 - Aging caregivers may expect a sibling/family member to care for the person with I/DD, but these wishes may not be communicated or agreed upon with the sibling/family member.
 - Difficult to understand the I/DD system, but there is not training available for sibling/family members to become prepared to be the primary caregiver once aging caregiver is no longer able to serve in the primary caregiver capacity.
- Aging caregivers need resources to develop long-term care plans for person with I/DD

- Need an option for aging caregivers and persons with I/DD to live together in the same facility or home with supports necessary to support persons with I/DD and persons without I/DD
- Need an option for persons with I/DD that provides a level of service less than an ICF, but more than a group home.

Improvement Recommendations for the I/DD System

- Funding needs to be secure. Planning cannot occur if there is a threat to the iBudget and Medicaid annually
- I/DD system is difficult to navigate and convoluted
- Better interagency coordination of services
- Increased funding is needed. Lack of funding means people are on the waitlist and unable to receive services
- A ranking system or way of scoring service providers is needed so caregivers and persons with I/DD can find quality providers
- Rigorous training for support care coordinators and providers is needed
- Must improve quality of services for persons with I/DD
- Expanded options for congregate living that accommodate needs of aging caregiver and their family member together

SURVEYS

METHODOLOGY

An electronic survey was developed to poll persons with I/DD or their designated representative about service utilization, identification of unmet needs, reasons for the barriers experienced, and issues of importance to persons with I/DD. To be eligible to take the survey, individuals must have been 18 years of age or older, reside in Florida and be a self-advocate (i.e., person with a developmental disability) or their designated representative who is also 18 years of age or older. Individuals who did not meet the aforementioned criteria were not included in the data analysis. The survey included six (6) questions and five (5) demographic items. The Qualtrics® web-based surveying platform was used to deliver the survey and collect responses. The survey instrument was tested for readability. A Spanish language version was also available. Prior to deployment, the electronic versions of the survey were pre-tested for functionality and ease of use.

A related survey was developed to collect input specifically from the family members and caregivers of persons with I/DD. Survey items included: service utilization, unmet needs, barriers experienced by the self-advocate in their care, as well as questions on specific needs and challenges for the caregiver. The survey had seven (7) questions and five (5) demographic items on the self-advocate in their care and six (6) demographic items on the family member and caregiver. As with the self-advocate survey, the Qualtrics® web-based surveying platform delivered the survey and collected responses. A Spanish language version was also available. Both the English and Spanish versions were pre-tested for functionality and ease of use and were available in electronic formats only.

A convenience sampling approach (respondents are selected based on accessibility and willingness to participate) was utilized for collecting survey responses. Both the self-advocate and caregiver/family member survey went live on March 16, 2020 and remained available through April 20, 2020. Through professional contacts and FDDC's public relations firm, the survey links were shared and promoted throughout Florida. When the self-advocate survey closed, there had been 296 survey log-ins, which yielded 121 complete, eligible surveys for analysis. The general demographic factors collected on the self-advocate survey respondents are presented in Table 12 below. Survey results are presented in the tables and figures that immediately follow.

The caregiver/family member survey garnered 748 log-ins that netted 553 complete, eligible surveys for analysis. Those results are presented in Tables 12-15 and Figures 19-21 below.

OBSERVATIONS FROM THE SELF-ADVOCATE SURVEY

Tables and figures below summarize the responses to the overarching questions that were asked of self-advocates or their designated representatives. There were 121 eligible, completed surveys

included in the analysis. In general, the top ten ranked responses for each question are presented. Each figure shows the percentage of self-advocates who indicated the given response for a question.

Questions on the following topics are included in the analysis:

- Services used in the past two years in Florida by the self-advocate
- Service areas where self-advocate had unmet needs
- Reasons for unmet needs for select services
- Services needed in the next 12 months

TABLE 13. DEMOGRAPHICS OF SELF-ADVOCATE SURVEY RESPONDENTS, 2020

Demographics	Providers and Partners N = 121	
Age of Self-Advocate	Number	Percent
18-29 years	37	30.6
30-39	24	19.8
40-49	26	21.5
50-59	16	13.2
60-64	7	5.8
65-69	9	7.4
70 and older	2	1.7
Gender of Self-Advocate		
Male	65	53.7
Female	55	45.5
Transgender	0	0
Other	0	0
Prefer not to answer	1	0.8
Race of Self-Advocate		
Asian Pacific Islander	1	0.8
Black or African American	9	11.0
American Indian/ Alaskan Native	0	0
White	96	79.4
2 or More Races	3	2.5
Multiracial/ Multiethnic	1	1.4
Other	8	6.6
Prefer not to answer	0	0
Hispanic Ethnicity of Self-Advocate		
Hispanic	28	23.0

Demographics	Providers and Partners N = 121	
Non-Hispanic	93	77.0
Prefer not to answer	0	0
Where Self-Advocate Lives		
Group Home	11	9.0
Family Home	60	49.6
Intermediate Care Facility (ICF/DD)	1	0.8
Own Home or Apartment	47	38.9
Assisted Living or Nursing Home	2	1.7
Homeless	0	0

Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

“Do you (self-advocate) know what services you can get?” OR Does the person with a developmental disability know what services he/she can get?” AND “Is it easy for you (self-advocate) to get the services you need? OR Is it easy to get the services the person with a developmental disability needs?”

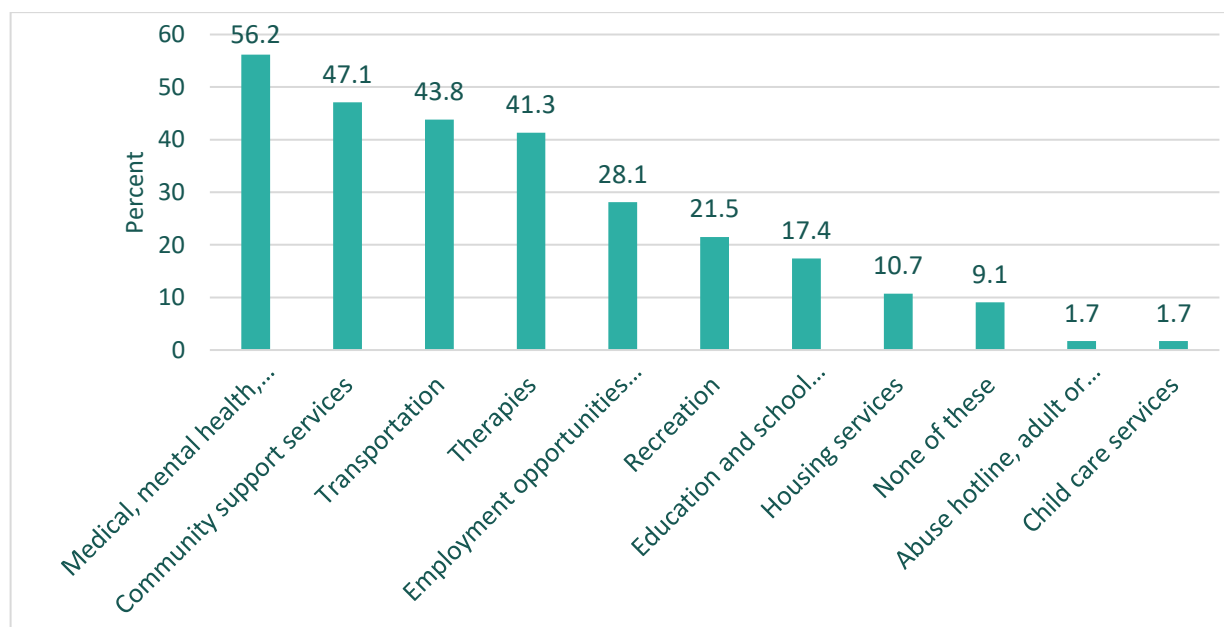
TABLE 14. SELF-ADVOCATE KNOWS WHAT SERVICES HE/SHE CAN GET AND EASE OF GETTING SERVICES, BY PERCENT, 2020

Question	percent		
	Yes	Kind of	No
Self-advocate knows what services he/she can get?	22.3	37.2	40.5
Easy to get needed services?	33.5	35.5	31.0

Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

“What services have you (self-advocate) used in Florida in the past two (2) years? (Select all that apply)” OR “What services has the person with a developmental disability used in Florida in the past two (2) years? (Select all that apply.)”

FIGURE 19. SERVICES USED IN THE PAST TWO YEARS IN FLORIDA BY SELF-ADVOCATE, BY PERCENT, 2020



Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

“Do you (self-advocate) receive all the services you need?” OR “Does the person with a developmental disability receive all the services he/she needs?”

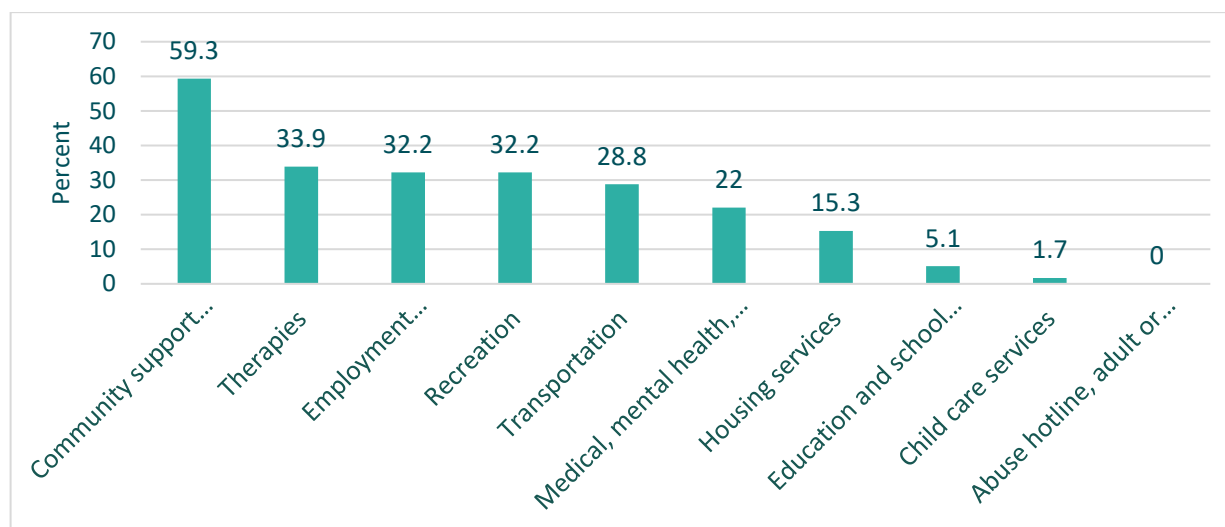
TABLE 15. SELF-ADVOCATE GETS NEEDED SERVICES, BY PERCENT, 2020

Get All Needed Services?	
Yes	51.3 percent
No	48.7 percent

Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

“In the past two (2) years, in what areas were your (self-advocate) needs not met? (Select all that apply.)” OR “In the past two (2) years, in what areas were the needs of the person with a developmental disability not met? (Select all that apply).”

FIGURE 20. UNMET NEEDS OF THE SELF-ADVOCATE IN PAST 2 YEARS BY SERVICE AREA AS REPORTED BY THOSE WITH UNMET NEEDS, 2020



Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

“Why was the need in the service area unmet?”

TABLE 16. REASONS FOR UNMET NEEDS FOR SELECT SERVICES, BY PERCENT, 2020

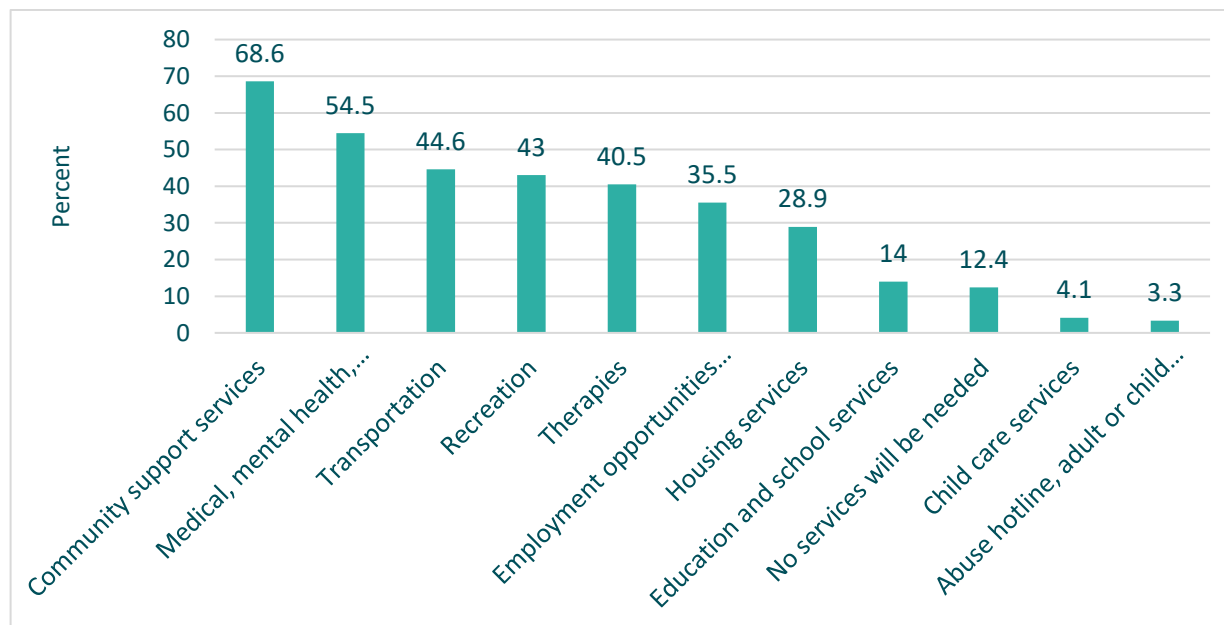
Reasons	Employ- ment	Health Care	Therapy	Educa- tion	Housing	Commu- nity Svcs	Recrea- tion	Transpor- tation
	Percent							
Cost	0	60	30.8	0	40	12.5	33.3	12.5
Waiting list	20	40	15.4	100	0	25	0	0
Accessibility	20	0	30.8	0	20	31.3	22.2	12.5
Transportation	40	0	7.7	0	0	6.3	22.2	N/A
No providers	20	0	30.8	0	0	18.8	55.6	25.8
Appointment availability	0	0	0	0	0	6.3	0	12.5
Service location	0	40	30.8	100	20	6.3	11.1	12.5
Service times	0	0	7.7	0	0	6.3	11.1	25.0
Ineligible for service	0	20	30.8	0	20	6.3	0	37.8

Note: Top rated unmet need is highlighted.

Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

**“What services will you (self-advocate) need in the next 12 months? (Select all that apply.)” OR
“What services will the person with a developmental disability need in the next 12 months? (Select all that apply.)”**

FIGURE 21. SERVICES NEEDED BY THE SELF-ADVOCATE IN THE NEXT 12 MONTHS, 2020



Source: FDDC Self-Advocate Survey, 2020, Prepared by: WellFlorida Council, 2020

KEY FINDINGS FROM SELF-ADVOCATE SURVEY

- Half of self-advocates who responded to the survey did not get the services they need; most frequently these included
 - Community support
 - Therapies
 - Employment and job training
 - Recreational opportunities
- Only 25 percent of self-advocates know what services they can get
- Only 20 percent of self-advocates said it was easy to get services
- Services self-advocates will need in the next 12 months include: community support services; medical, mental health, dental care, and wellness supports; transportation; recreation; and therapies

OBSERVATIONS FROM THE CAREGIVER/FAMILY MEMBER SURVEY

Figures below summarize the responses to the overarching survey questions. In general, the top ten responses for each question are presented. Questions on the following topics are included in the analysis:

- Services used and unmet needs in service areas
- Reasons for unmet needs
- Most important service areas for the person with developmental disabilities in your care
- Service needs of the person with developmental disabilities in the next 12 months
- Top three (3) service or resource needs as a caregiver
- Top three (3) critical issues faced as a primary caregiver for the person with developmental disabilities

Tables and figures show the percentage of respondents who completed the survey and indicated the given response for a question accompanied by a ranking, if appropriate. The number of completed surveys included in the analysis was 553.

TABLE 17. DEMOGRAPHICS OF CAREGIVER/FAMILY MEMBER SURVEY RESPONDENTS, FROM COMPLETED ELIGIBLE SURVEYS, 2020.

Demographic Indicator	Number	Percent
	N = 553	
Age of Caregiver/Family Member		
18-29	39	7.1
30-39	75	13.6
40-49	107	19.4
50-59	144	26.0
60-64	71	12.8
65-69	66	11.9
70 or older	51	9.2
Gender of Caregiver/Family Member		
Male	51	9.2
Female	494	89.3
Transgender	0	0
Prefer not to answer	0	0

Demographic Indicator	Number	Percent
	N = 553	
Other	0	0
Race of Caregiver/Family Member		
American Indian/ Alaskan Native	2	0.4
Asian	9	1.6
Black or African American (Non-Hispanic)	48	8.7
Pacific Islander or Native Hawaiian	0	0
Two or More Races	22	4.0
Some Other Race	14	2.4
White	427	77.2
Prefer not to answer	31	5.6
Hispanic Ethnicity		
Not of Hispanic Origin	444	80.3
Hispanic	83	15.0
Prefer not to answer	26	4.7
Florida Residency of Caregiver/Family Member		
Florida Resident	552	99.8
Do not live in Florida	1	0.2
Primary Caregiver of Person with Developmental Disabilities		
Yes, survey respondent is primary caregiver	479	86.6
No, survey respondent is not primary caregiver	74	13.4
Relationship to Person with Developmental Disabilities (may select more than one relationship)		
Parent	455	82.3
Grandparent	10	1.8
Brother/Sister	22	4.0
Legal Guardian Advocate or Legal Guardian	147	26.6
Other (1 each: Vocational Rehabilitation Case Mgr, Special Needs Advocate, Teacher, Respite Provider, Waiver Support Coordinator, Intake Specialist, In-home support, Group Home worker, ALF, Case Mgr, Niece, Nephew, In-law, Foster Parent, Financial Mgr, Power of Attorney; 2 each:	58	10.5

Demographic Indicator	Number	Percent
	N = 553	
Aunt, Cousin, Direct Care Support, Staff, Supported Living Coach; 3 each: Friend, Provider; 11: Caregiver; 14: Unspecified)		

Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020.

TABLE 18. DEMOGRAPHICS OF THE PERSON WITH DEVELOPMENTAL DISABILITIES FOR WHOM SURVEY RESPONDENT IS CAREGIVER/FAMILY MEMBER, 2020

Demographic Indicator	N = 553	
	Number	percent
Age of Person with Developmental Disabilities		
Less than 5 years	12	2.2
5-17	140	25.3
18-21	61	11.0
22-29	123	22.2
30-39	114	20.6
40-49	52	9.4
50-59	34	6.1
60-64	10	1.8
65-69	4	.8
70 or older	3	.5
Gender of Person with Developmental Disabilities		
Male	326	59.0
Female	217	39.2
Transgender	0	0
Prefer not to answer	8	1.4
Not listed (2 each: Both Male and Female)	2	0.4
Race of Person with Developmental Disabilities		
American Indian/ Alaskan Native	2	0.4
Asian	6	1.0
Black or African American	48	8.7
Pacific Islander or Native Hawaiian	0	0

Demographic Indicator	N = 553	
	Number	percent
Two or More Races	43	7.8
Some Other Race	11	2.0
White	413	74.7
Prefer not to answer	30	5.4
Hispanic Ethnicity of Person with Developmental Disabilities		
Not of Hispanic Origin	439	79.4
Hispanic	87	15.7
Prefer not to answer	27	4.9
Where Person with Developmental Disabilities Lives		
Group Home	54	9.8
Family Home	409	74
Intermediate Care Facility (ICF/DDP)	4	0.7
His/Her Own Apartment/Home	75	13.6
Assisted Living Facility or Nursing Home	2	0.4
Homeless	0	0
Other (6: Independent Supported Living, 1 each: Foster Home, Prison)	8	1.4

Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020.

TABLE 19. COUNTY OF RESIDENCE OF SURVEY RESPONDENTS, CAREGIVER/FAMILY MEMBER AND PERSON WITH DEVELOPMENTAL DISABILITIES, 2020

County of Residence	N = 553			
	Caregiver/Family Member		Person with Developmental Disabilities	
	Number	percent	Number	percent
Alachua	6	1.0	6	1.0
Baker	0	0	1	0.2
Bay	0	0	0	0
Bradford	1	0.2	0	0
Brevard	22	4.0	19	3.4
Broward	40	7.2	39	7.0

County of Residence	N = 553			
	Caregiver/Family Member		Person with Developmental Disabilities	
	Number	percent	Number	percent
Calhoun	2	0.4	2	0.4
Charlotte	3	0.5	0	0
Citrus	7	1.3	7	1.3
Clay	8	1.4	7	1.3
Collier	10	1.8	10	1.8
Columbia	1	0.2	0	0
Miami-Dade	41	7.4	39	7.0
DeSoto	0	0	0	0
Dixie	0	0	1	0.2
Duval	27	4.9	32	5.8
Escambia	2	0.4	2	0.4
Flagler	1	0.2	1	0.2
Franklin	0	0	0	0
Gadsden	0	0	1	0.2
Gilchrist	0	0	0	0
Glades	1	0.2	1	0.2
Gulf	0	0	0	0
Hamilton	0	0	0	0
Hardee	2	0.4	0	0
Hendry	0	0	0	0
Hernando	4	0.8	3	0.5
Highlands	1	0.2	3	0.5
Hillsborough	35	6.3	31	5.6
Holmes	0	0	0	0
Indian River	4	0.8	6	1.0
Jackson	1	0.2	0	0
Jefferson	0	0	1	0.2
Lafayette	0	0	0	0
Lake	8	1.4	10	1.8
Lee	21	3.8	22	4.0

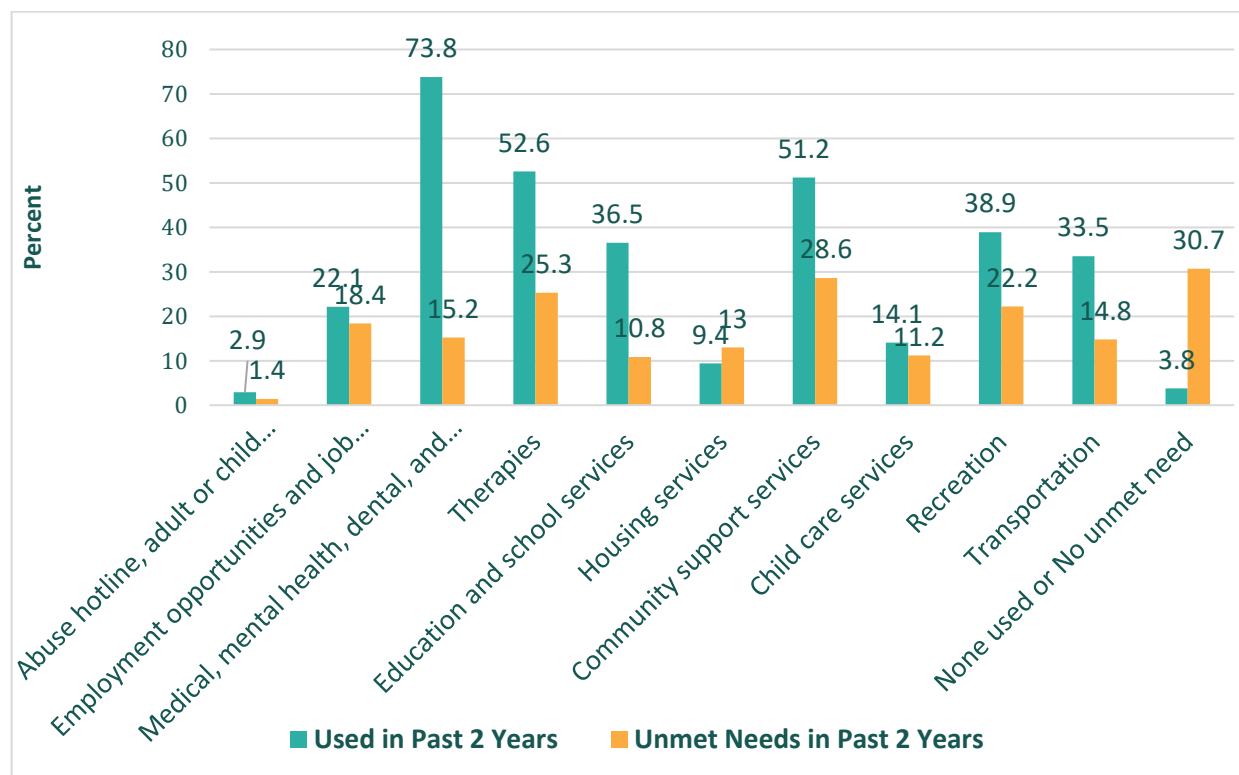
County of Residence	N = 553			
	Caregiver/Family Member		Person with Developmental Disabilities	
	Number	percent	Number	percent
Leon	17	3.1	16	2.9
Levy	0	0	0	0
Liberty	0	0	0	0
Madison	0	0	1	0.2
Manatee	7	1.3	6	1.0
Marion	6	1.0	6	1.0
Martin	6	1.0	7	1.3
Monroe	0	0	0	0
Nassau	1	0.2	1	0.2
Okaloosa	8	1.4	8	1.4
Okeechobee	12	2.2	12	2.2
Orange	30	5.4	33	6.0
Osceola	3	0.5	3	0.5
Palm Beach	46	8.3	45	8.1
Pasco	19	3.4	21	3.8
Pinellas	25	4.5	24	4.3
Polk	26	4.7	27	4.9
Putnam	1	0.2	1	0.2
St. Johns	10	1.8	8	1.5
St. Lucie	19	3.4	18	3.3
Santa Rosa	5	0.9	5	0.9
Sarasota	20	3.6	25	4.5
Seminole	20	3.6	19	3.4
Sumter	6	1.0	4	0.7
Suwannee	4	0.7	4	0.7
Taylor	0	0	1	0.2
Union	0	0	0	0
Volusia	13	2.4	12	2.2
Wakulla	0	0	0	0
Walton	0	0	0	0

County of Residence	N = 553			
	Caregiver/Family Member		Person with Developmental Disabilities	
	Number	percent	Number	percent
Washington	0	0	1	0.2
I don't know	1	0.2	1	0.2

Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

“What services has the person with a developmental disability used in Florida in the past 2 years? Select all that apply.” AND “In the past 2 years in what areas did the person with a developmental disability not have their needs met? (Select all areas that apply.)”

FIGURE 22. SERVICES USED AND UNMET NEED IN SERVICE AREAS AS REPORTED BY SURVEY RESPONDENTS WHO ARE CAREGIVERS/FAMILY MEMBERS OF PERSONS WITH I/DD, BY PERCENT OF RESPONSES, 2020



Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

“Why was their need for select services not met (Select all reasons).”

TABLE 20. REASONS FOR UNMET NEEDS FOR SELECT SERVICES AS REPORTED BY CAREGIVER/FAMILY MEMBER SURVEY RESPONDENTS, BY PERCENT, 2020

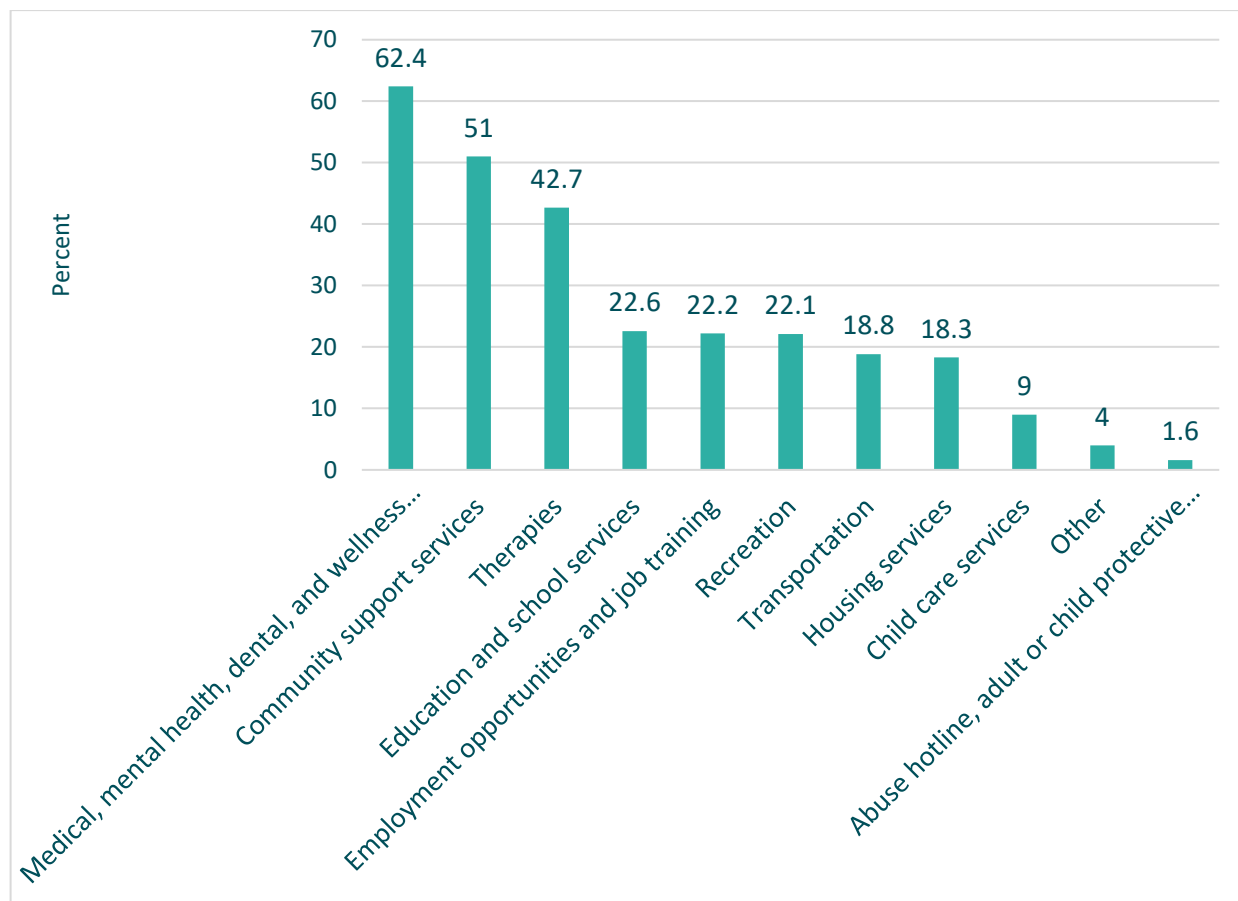
Reasons	Employ- ment	Health Care	Therapy	Educa- tion	Housing	Communi- ty Svcs	Child Care	Recrea- tion	Transporta- tion
	Percent								
Cost	6.9	27.8	35	10	36.1	21.5	32.3	28.5	15.6
Waiting list	14.7	27.4	31.4	15	37.5	27.8	19.4	8.9	6
Accessibility	24.5	22.6	20	26.7	15.3	25.9	19.4	22.8	19.5
Transportation	14.7	10.7	5.7	3.3	2.8	8.2	3.2	9.8	N/A
No providers	28.4	53.6	30.7	13.3	33.3	31.6	32.3	28.5	30.5
Appointment availability	15.7	15.5	16.4	8.3	4.2	8.9	14.5	2.4	6
Service location	6.9	9.5	10.7	3.3	6.9	12.7	10	20.3	9.8
Service times	5.9	4.7	42.1	6.7	4.2	9.5	1.6	14.6	12.1
Ineligible for service	19.6	8.3	17.9	16.7	13.9	15.2	19.4	6.5	15.6

Note: Top 2 reasons in each service area are highlighted

Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

“What were the top three (3) most important service areas for the person with a developmental disability in your care? (Select three.)”

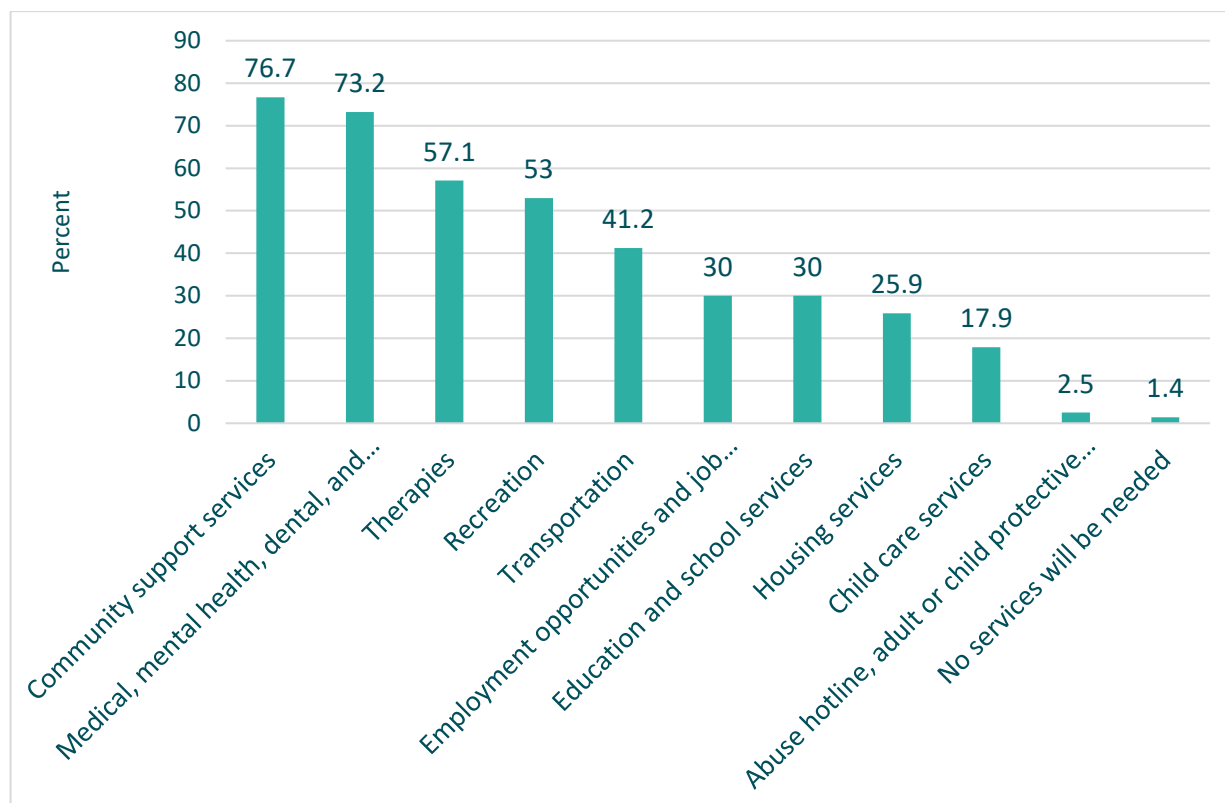
FIGURE 23. TOP 3 MOST IMPORTANT SERVICE AREAS FOR THE PERSON WITH DEVELOPMENTAL DISABILITIES IN THEIR CARE AS REPORTED BY CAREGIVER/FAMILY MEMBER SURVEY RESPONDENTS, 2020



Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

“What services do you believe the person with a developmental disability will need in the next year (12 months)? (Select all that apply.)”

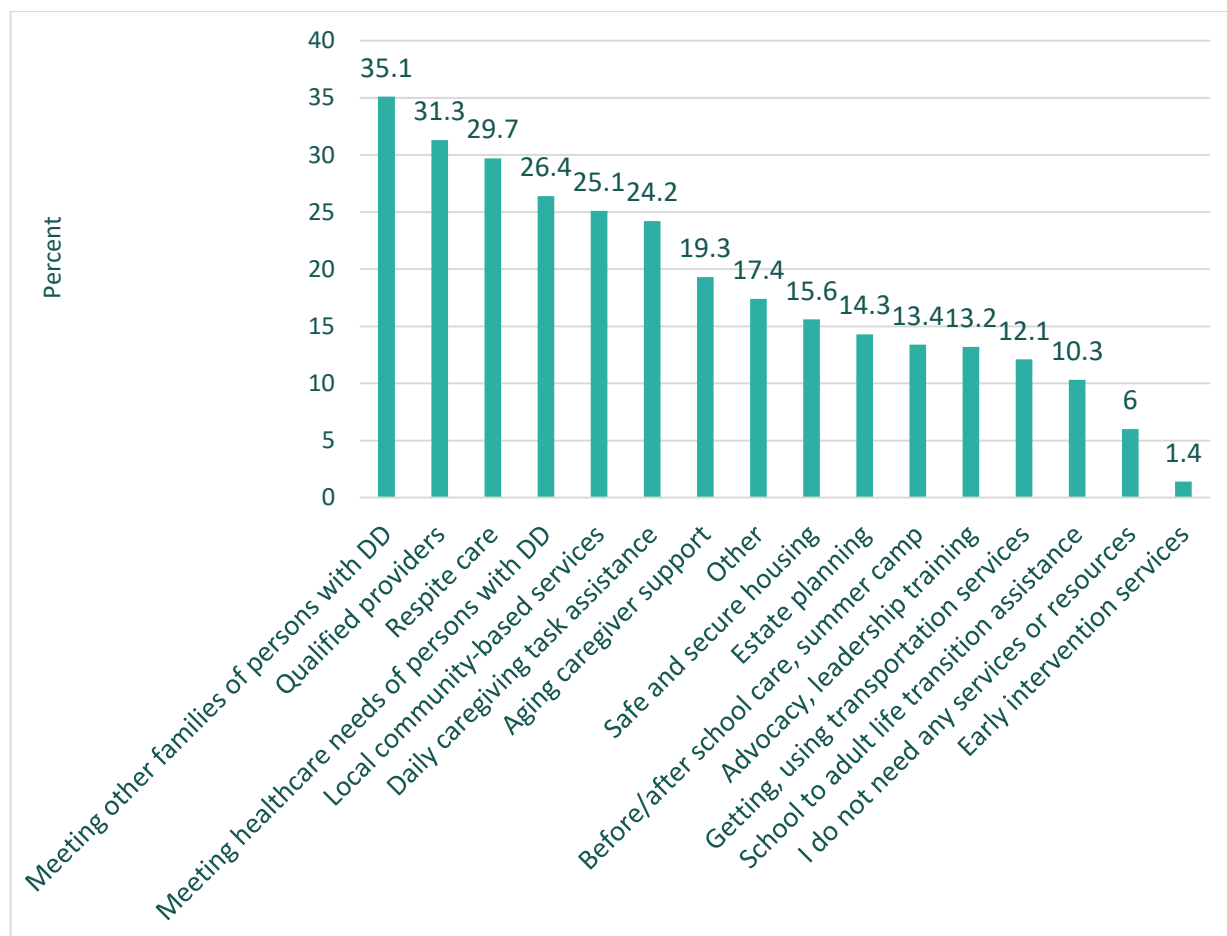
FIGURE 24. SERVICES NEEDED IN THE NEXT 12 MONTHS BY THE PERSON WITH DEVELOPMENTAL DISABILITIES IN THEIR CARE AS REPORTED BY CAREGIVER/FAMILY MEMBER SURVEY RESPONDENTS, BY PERCENT, 2020



Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

“What are the three (3) top services or resources you need as a caregiver to be able to best assist the person with a developmental disability? (Select three.)”

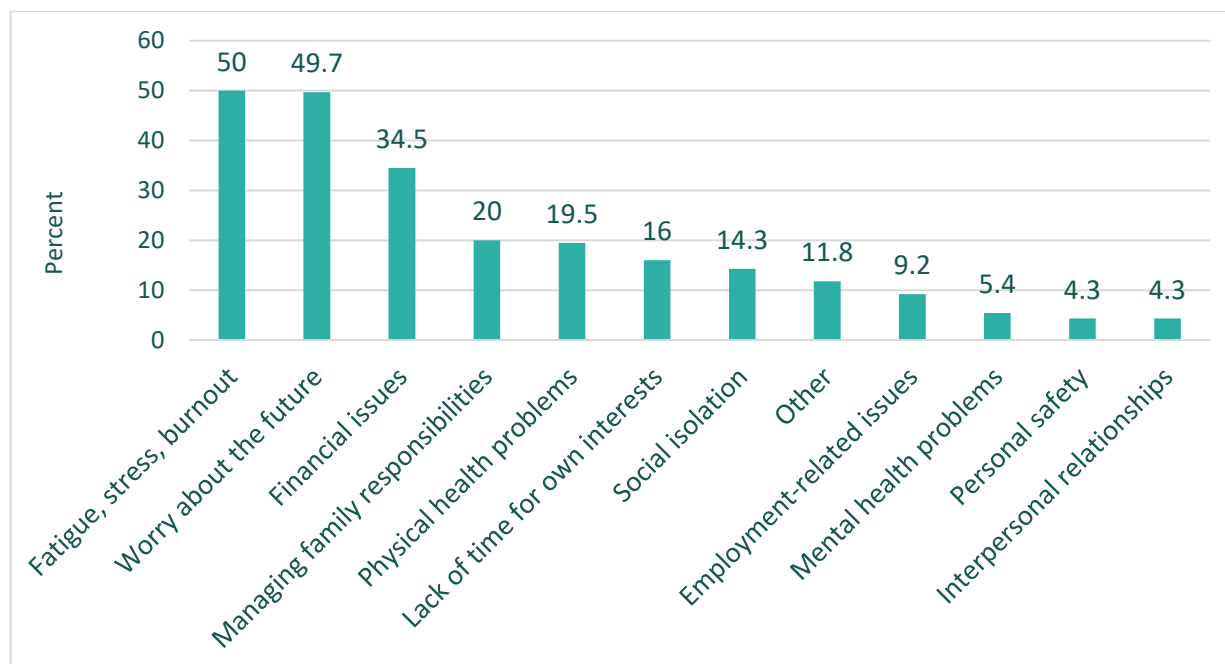
FIGURE 25. THREE TOP SERVICE OR RESOURCE NEEDS AS A CAREGIVER REPORTED BY CAREGIVER/FAMILY MEMBER SURVEY RESPONDENTS, BY PERCENT, 2020



Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

“What are the three (3) critical issues you face as the primary caregiver of a person with a developmental disability? (Select three issues.)”

FIGURE 26. THREE CRITICAL ISSUES FACED AS PRIMARY CAREGIVER OF PERSON WITH DEVELOPMENTAL DISABILITIES, REPORTED BY CAREGIVER/FAMILY MEMBER SURVEY RESPONDENTS, 2020



Source: FDDC Caregiver/Family Member Survey, 2020, Prepared by: WellFlorida Council, 2020

KEY FINDINGS FROM CAREGIVER/FAMILY MEMBER SURVEY

- Most common reasons for unmet service needs include lack of providers and cost
- Top resource needs as caregiver include connections to other families of persons with I/DD, finding qualified providers, and respite care
- Critical issues as primary caregiver included fatigue/stress/burnout, worry about the future, and financial issues

KEY INFORMANT INTERVIEWS

WellFlorida Council worked with the Florida Developmental Disabilities Council leadership to identify key informants based on their insights and experiences into policy, funding, education, advocacy, the

service delivery system and/or general perspectives regarding persons with I/DD in Florida. The complete list of key informants who were interviewed by WellFlorida Council is provided in Table X.

TABLE 21. KEY INFORMANTS, 2020

Name	Organization/Agency	Position
Jeffrey Brosco, MD, PhD	Mailman Center for Child Development and University of Miami School of Medicine	Associate Director
Carter Burton	Florida Housing Coalition	Technical Advisory
David Darm	Florida Commission for the Transportation Disadvantaged	Executive Director
Tony DePalma	Disability Rights Florida	Director of Public Policy
Liz Dudek	Greenberg Traurig, P.A.; Former Secretary of the Florida Agency for Health Care Administration	Legislative Consultant to FDCC
Margaret Lynn Duggar	Margaret Lynn Duggar and Associates	Owner/Principal
Kirk Hall	The Arc of Florida	Chief Executive Officer
Shevaun Harris	Florida Agency for Health Care Administration	Assistant Deputy Secretary for Medicaid Policy and Quality
Tim McCann	Florida Alliance for Assistive Services and Technology	Information, Referral and Services Specialist
Barbara Palmer	Florida Agency for Persons with Disabilities	Director
Jan Pearce	Department of Education, Division of Vocational Rehabilitation	Program Administrator
Elizabeth Perkins, PhD, RNLD, FAAI/DD, FGSA	Florida Center for Inclusive Communities at the University of South Florida	Associate Director
Greg Ungru	Florida Department of Elder Affairs	Deputy Secretary
Suzanne Sewell	Florida Association of Rehabilitation Facilities	President and Chief Executive Officer
Jean Sherman, DEd, RN	Mailman Center for Child Development and University of Miami School of Medicine	Voluntary Associate Professor

Name	Organization/Agency	Position
Monica Verra-Tirado	Florida Department of Education, Bureau of Exceptional Education and Student Services	Bureau Chief

Source: FDDC and WellFlorida Council, April/May 2020.

METHODOLOGY

The structured interview tool was comprised of thirteen (13) questions regarding the overall system of services for persons with I/DD; the biggest issues facing self-advocates and persons with I/DD in Florida; and discussion on the potential areas of priority and partnership for the FDDC. The structured interview tool, seen in the Appendix, was developed by WellFlorida Council in concert with the leadership of the FDDC.

The formal structured interview took between 1 and 1.5 hours to administer and was conducted by phone, ZOOM meeting, or Microsoft TEAMS meeting. Some key informants preferred to complete their interview questions in writing, and then the “interview” consisted of WellFlorida following up with the key informant in order to glean more clarity or detail from the written responses. The purpose of the key informant interviews was neither to get direct quotes from individuals nor to obtain a statistically representative sample of perspectives. Rather, the purpose was to generate a list of key themes from a group of varying, highly-informed individuals, as a means to gain insight into the systems and needs of persons with I/DD and their families and caregivers.

The *Response Summary* section that follows presents each of the major structured interview questions and catalogs, through paraphrasing and via bulleted lists, the key and most frequently occurring responses for each question.

Question: What does “systems change” mean to you?

- Understanding how organizations work and interact to get outcomes.
- Not just policy change but process change. If systems change does not mean policy change, then in order to achieve state policy change, we must connect with local governments administering local, state, and federal programs to change their processes first.
- Trying to tackle a very large social problem that takes a big collective and collaboration to create meaningful change as a group.

- It is the “goal line” of policy work. Structural level change that is driven by policy based on a fair, accurate, and honest assessment of current system and subsequent development of a roadmap for fundamental changes.
- Can be as simple as changing a process or re-directing responsibility. Really can mean a variety of things as systems can vary in scope and size.
- Refers to a process whereby significant improvements can be advocated for and implemented to improve the impacts and results for the persons being served.
- Advancement to better accommodate and provide more access and services.
- In terms of systems for persons with I/DD, systems change is looking at different interactions people have with the system and re-designing processes to maximize the support and fostering of rights and access.
- Enhancing something for the better based on what is currently needed (demonstrated through needs assessment).
- To fundamentally alter the way society looks at an issue.
- New pattern or system based on assessed needs whereby the response to those needs is to design changes to impact the big picture.
- An effort to address a problem or unmet need experienced by individuals with I/DD through long-term and sustainable modification of policies, procedures, processes, laws, rules, funding, and/or other means.
- Adapting formal services to current needs and adapting future services based on ongoing needs assessment.
- Evaluating current service options and resources that are available to meet the needs of individuals with developmental disabilities; identifying gaps; and responding to the findings to promote improvements or changes to better meet the needs of individuals with I/DD.
- Making a positive improvement in a policy or service delivery at the state level across the system.
- Comprehensive look at all aspects of a system (infrastructure, resources, policies, timing, people, drivers of change, barriers to change, etc.) to make changes.

Question: What part of system needs changing?

- Dramatic drop-off in access to services once persons with I/DD age out of child and youth services (age 21+).
- Disaster planning for persons with I/DD. Local governments may not be prepared for transporting, housing, or providing essential services to persons with I/DD who are impacted.
- Medical model that underlies I/DD services holds individuals back from independence.

- Benefit structure and rules of benefits, such as SSI and Medicaid, deter employment, as folks may lose benefits fully even with moderate levels of employment and income.
- Transportation and employment.
- Find systems and processes for being able to look at the whole picture to determine truly who is being served; who is not being served; and how persons with I/DD are being served.
- Public systems such as housing, transportation, and health care need to be more accommodating and personalized for persons with disabilities, as does employment in the private and public sectors.
- Employment (especially changing rules and regulations, such that persons with I/DD can retain more of their benefits when pursuing employment).
- Workforce development (both for those that serve persons with I/DD and employment opportunities for persons with I/DD).
- Limited housing.
- Adaptive devices are available and compensated but sometimes modifications to make those devices useable are not (e.g., wheelchairs and scooters are available and paid for but lifts so that autos and vans can be modified to accommodate those wheelchairs and scooters are not).
- Financial disincentives for working.
- System for training providers of services for persons with I/DD.
- Agency coordination (e.g. children with I/DD typically require services from multiple state agencies, so it is essential for agencies to work together to meet needs).
- Persons with I/DD and a co-occurring mental health diagnosis require the development and deployment of a system specifically designed to meet their complex needs (includes maladaptive behaviors and dual diagnosis).
- iBudget waiver needs to be provided based upon cost projections from Social Services Estimating Conference.
- Individual iBudgets for waiver clients must be based on comprehensive assessment of personal need.
- Ensure iBudget waiver is the payor of last resort by engaging community and faith-based programs.
- Wage scale for persons who provide services to persons with I/DD to promote more quality and consistency of services.
- iBudget waiver and support system is designed to promote independent living but is not providing the basics for so many.

- System of services reduces profoundly for many once they age past the educational system and into adulthood.
- Design and promote systems of support with true choice and multiple options.
- A continuum of services is needed, specifically across the intensity of service(s) required and the lifespan of persons with I/DD.
- Ensure true “person-centered” planning.
- Planning for the aging of adults with I/DD and their aging caregivers.
- Handoff of persons with I/DD from school and educational system-based programs and services to those for adults outside of the school or educational system
- School and educational system has prepared many well for independence but beyond the school and educational system, the services for young adults and those in various stages of adulthood have not been as well developed or are as widely available.

Question: Biggest issue that self-advocates or persons with I/DD are facing today?

- Major drop-off in system of (health) care from child/school/teenager to young adult.
- Lack of resources on how to apply for essential services and who provides services at the local and state level (housing especially).
- Maintaining a level of independence through having a home; relationships; and fulfilling job or life experiences to the greatest extent possible.
- The fact that there are so many issues is the biggest issue.
- Still not a good understanding of the population as a whole and its needs (perhaps for youth and children this is better known and understood).
- Still not great data on the number of persons who have actually have I/DD so it is difficult to estimate system needs.
- Aging of the person with I/DD. Like everyone, persons with I/DD are living longer and substantially outliving the support structure of their families and caregivers.
- The tension between the fear of institutionalization as a policy re-appearing and the concept of developing planned communities for persons who may not have a family or caregiver support structure or who have outlived that structure (like seniors who live in planned adult communities, continuing care retirement communities, ALFs or SNFs).
- Parents and caregivers do not know about aging issues of their loved one with I/DD and the services available to their loved one and themselves as they both age.

- There are a multitude of organizations that provide self-advocates with services but these groups do not have a unified messaging across the spectrum of I/DD.
- In terms of access to services, persons with I/DD “drop off a cliff” after the age of schooling (after 21).
- For a substantial and ever-growing proportion of the persons with I/DD population, their caregivers and families are aging beyond their ability to continue being able to provide caregiving effectively or at all.
- Access to transportation.
- Access to assistive technologies.
- The threat of poverty or not having enough income.
- Low funding levels and the resultant shortage of services available that plays out in the extensive waitlist.
- Availability of services and transition into other services or service systems is not uniform and smooth across the lifespan of a person with I/DD.
- Underfunding of the Medicaid waiver/iBudget and resultant lack of access to services for many thousands.
- The scarcity of resources is always a challenge and limits the number of individuals who receive services (i.e., the iBudget waitlist).
- Threats to the DD waiver.
- The right supports to be as independent as possible: transportation; friends; community connections; education; employment; commitment from community; commitment from government; etc.
- Services and transition assistance are not available at the same levels across the lifespan of a person with I/DD.

Question: Biggest issue that families and caregivers of persons with I/DD are facing today?

- Parents and caregivers themselves aging. Who will take care of my loved one when I need more care than they do or when I am gone?
- Difficult for family members or caregivers to continue to work while caring for an individual, thus limiting their income which exacerbates difficulty in meeting basic living expenses.
- Families’ and caregivers’ concerns for safety as their loved ones are afforded opportunities to cultivate independence. A paradox in that family members and caregivers most often want a level of independence for their loved one but oftentimes the concern for safety can have a smothering effect on the development of independence.

- Understanding educational options. When a family member is at a young age, that is when the family or caregivers' voice and insight is most important, as decisions at a young age can ripple through life (but this requires an informed and engaged family member or caregiver).
- Uncertainty of the future both they and their loved one's age. What will happen with my child when I am not here?
- Knowledge of elderly caregivers about the availability of services as they and their adult children age and how to access those services.
- There is tremendous difficulty for families and caregivers to understand the complex options that are available to them and how to apply for them. There are difficulties for parents and caregivers of children and school-aged youth, but this problem becomes even more magnified for parents and caregivers and adults as the quality of transition planning varies from school district to school district across the state.
- Parents and caregivers do not fully understand the aging issues of their loved ones with I/DD and the services available to their loved ones and themselves as they both age.
- The fact that, in terms of services, persons with I/DD "drop off a cliff" after the age of schooling (after 21) puts even more pressure on families and caregivers.
- Stigma of institutionalization versus the need for a place to live. This occurs once a person with I/DD either outlives their family members or caregivers, or their family members or caregivers age such that the family members or caregivers may have more caregiving needs than the person with I/DD.
- Access to transportation.
- Access to assistive technologies.
- In this era in which we are facing reduced provider rates and services being cut, loved ones cannot get services, thus placing more of a caregiving burden on caregivers and families. Thus, families and caregivers need more respite care to alleviate this burden and to help families remain intact.
- Family members are concerned that the state funding levels do not meet the needs that all persons with I/DD have.
- Innovative residential solutions are needed, though there is tension between the concept of independence and the echoes of institutionalization that innovative residential solutions bring to mind for many. "What happens when I die?" is not only a question of where (housing) a loved one with I/DD will live but how (independence) will live.
- The aging caregiver situation is the biggest issue. Florida leads the nation in the number of seniors and the proportion of the population who are seniors. As such, Florida should be leading the

nation in addressing aging issues in general, and so too should it be a leader in the aging issues of persons with I/DD and their aging family members and caregivers.

- What happens to loved ones when caregivers pass? More resources are needed that promote plans that ensure continuity of care when individuals lose their caregivers.
- Adults with I/DD who need services are often lost in the advocacy message, as children and youth are often the centerpiece of advocacy efforts, as they are responded to more fervently by those key leaders who are targets of advocacy and education.
- Caregiving fatigue. 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?"

Question: What should be FDDC's systems change focus?

- Limited health care options for adults with I/DD (not enough providers with experience working with persons with I/DD and insurance coverage is lacking).
- Lack of a coordinated data system (that could include services received and outcomes of services received) significantly impacts policy change; agency coordination is less than it could be as there is no integrated data management system that accounts for persons with I/DD.
- Transportation (specifically investments in multi-modal choices).
- Wage issue for persons who serve I/DD population.
- Transportation, housing, and employment (the "holy trinity").
- FDDC can be data and needs assessment convener.
- Transportation accessibility and accommodation.
- The changing economy and the nature of employment for persons with I/DD.
- Poor transportation infrastructure.
- Access to basic rights such as voting.
- iBudget/DD waiver.
- Workforce development.
- Expand existing transportation efforts to all 67 counties.
- Training for providers of services for persons with I/DD.
- Support services for persons with I/DD with aging parents who are primary caregivers.
- Segregated employment and wage issues for persons with I/DD.

- Collaboration with the APD on advocacy for agency coordination; systems for persons with co-occurring mental health diagnoses; iBudget waiver issues; and workforce development issues.
- Preservation of the iBudget.
- Expansive proactive, rather than reactive, public messaging to policy changes for persons with I/DD and their service needs.
- Systems for aging persons with I/DD (especially for those persons that rely on aging caregivers).
- Development of a system that is responsible to all individuals with I/DD, not just what the ACL adopts as its priorities.
- Planning for the current and rapidly growing future needs of aging persons with I/DD and their aging caregivers.
- Metrics to measure opportunities for meaningful employment and placement into and utilization of safe, integrated housing.

Question: What are ways to improve partnerships with FDDC?

- Support a standing group at FDDC that works on health care issues.
- Advocacy and education on housing issues including fair housing, grants, development, community land trusts, housing summits, and disaster planning.
- Enhanced self-advocacy efforts.
- Creating a more fertile environment for collaboration (i.e., bringing back the regular stakeholders' call).
- Facilitating relationships with APD and AHCA, not just in and around legislative activity but throughout the year.
- Support for aging caregivers with adult children living at home.
- Fostering more collaboration outside the construct of Council meetings.
- Advocacy on transportation issues.
- Issues of persons with I/DD and co-occurring behavioral health issues.
- Collaboration with the APD on advocacy for agency coordination; systems for persons with co-occurring mental health diagnoses; iBudget waiver issues; and workforce development issues.
- Funding pilot projects as well as researching and sharing best practices related to service delivery models from around the state and nation.
- Elevate the prominence of the message of the needs of persons with I/DD.
- Foster environment of working together to address the overall needs of individuals with I/DD. There needs to be a reduction of in-fighting over exceptions to other agencies' service models.

- Bringing lifespan message to the advocacy process, regarding the needs of persons with I/DD and their caregivers, both of whom are aging.
- Communication of and accountability to long-term quality indicators.

Question: If FDDC could focus on only one service area, what would it be?

- Influence the transition of the health care sector from fee-for-service to value-based care and the impact this transition will have on persons with I/DD.
- A housing-first approach provides stability to address other issues.
- Creating a unified voice across the spectrum of I/DD.
- Educating and informing the Legislature on the design and operation of the iBudget waiver, including elimination of the waitlist.
- Overall system performance assessment and ongoing evaluation to inform system re-design and funding decisions.
- Aging issues and services for aging persons with I/DD and their aging family members and caregivers.
- Transportation.
- Lifespan transitions planning.
- Workforce development (both for persons that provide services to persons with I/DD and for opportunities for work for persons with I/DD).
- Services system development for those with most complex issues and those with co-occurring mental health diagnoses.
- Consistent services availability as persons with I/DD transition through various life stages.
- Research on evidence-based system improvements to inform public policy.
- Design of and advocacy for a comprehensive continuum of services that is truly responsive to the needs of all individuals with I/DD and the families.

Key Informant Interview Key Themes

While the structured interview tool was comprised of 13 questions, these questions can be comprised into three (3) main thematic domains:

- Biggest Issues for Persons with I/DD
- Biggest Issues of Families and Caregivers of Persons with I/DD; and
- Perspectives on Priority Areas of Focus for FDDC

Each key informant's responses were thoroughly analyzed and themes (those ideas, concepts and perspectives most frequently mentioned) identified. Once identified, these overarching themes for each domain were catalogued for each of the three thematic domains. Each of the three thematic domains and the overarching themes for each is provided below.

Biggest Issues for Persons with I/DD

- Transportation
- Limited funding and Threats to iBudget Waiver, including Waitlists
- Service Drop-offs or Non-Uniform Services Availability throughout Life Stages
- Transition Assistance throughout Life Stages
- Aging of Persons with I/DD and Aging of their Family Members and Caregivers who Provide Support
 - Long-term care planning

Biggest Issues of Families and Caregivers of Persons with I/DD

- Transportation
- Housing (Tension between Maximizing Independence and Renewed Fears of Institutionalization Issues Evoked by New Housing Concepts)
- Caregiver Fatigue and Burnout
- Knowledge of Services and How and When to Access, Ability to Access Services with limited resources
- Aging Family Members and Caregivers Who Eventually Cannot Provide Support or Need More Caregiving Support (in Some Cases) than Their Loved Ones with I/DD

Perspectives on Priority Areas of Focus for FDDC

- Provision of comprehensive services throughout lifespan for persons with I/DD, including long-term care planning related to aging issues and their aging family members/caregivers
- Workforce development for persons providing services to the I/DD population and workforce development of the I/DD population to improve their employment opportunities
- Development of a service system that assists those with the most complex issues including those with dual diagnosis, maladaptive behaviors, etc.
- Influence the transition of the healthcare sector from "fee-for-service" to "value-based service"
- System performance assessment and ongoing evaluation to inform system redesign and funding decisions on an ongoing basis, including evidence-based system improvements

Analysis of State Issues and Challenges

ELIGIBILITY CRITERIA FOR SERVICES

In Florida, eligibility criteria is set by the federal, state, or local agency providing the service and supports. Among the factors considered in criteria setting are applicable federal and/or state statutes and regulations, funding source requirements and limits, professional best practices, and the scope, scale, and purpose of the services and supports. Documentation of a standard process for eligibility criteria review and update by Florida state agencies was not found. The Agency for Persons with Disabilities (APD) through its searchable web portal, known as “Florida Navigator” (Florida Agency for Persons with Disabilities, n.d.) lists the eligibility criteria for programs and services. The table that follows presents the eligibility criteria for programs that are most commonly used by persons with I/DD in Florida.

Issues related to eligibility surfaced in the public input portion of the assessment, in both the focus groups and self-advocate and caregiver/family member surveys. Focus group participants expressed consternation at the difficulty in accessing program information relevant to eligibility criteria, whether in print, electronic, telephonic, or in person. This was compounded for non-English speaking families. They relayed that getting assistance with forms and required documentation, having questions answered about one’s specific case, and determining where one’s application was in the approval process were time-consuming, frustrating, and often ended without resolution. Self-advocate survey respondents reported issues with eligibility related to unmet needs for therapies and transportation. Eligibility for education programs, services, and supports was reported as a barrier to those services by caregiver/family member survey respondents.

TABLE 22. ELIGIBILITY CRITERIA FOR SELECT PROGRAMS, FLORIDA, 2020

Program	Eligibility Criteria	Services Offered
Assisted Living in Florida	<ul style="list-style-type: none"> • Eighteen years of age or older • No longer able to live independently in their own home or apartment • Need assistance or supervision when eating, walking, grooming or in the bathroom • Need assistance with medication(s) 	<ul style="list-style-type: none"> • Housing and Residential Options • Elderly Support • Nutrition • Housing and Residential Options

Program	Eligibility Criteria	Services Offered
	<ul style="list-style-type: none"> • Need routine, simple nursing services but not 24-hour nursing services • Need routine mental health services but not 24-hour nursing services 	
Bureau of Exceptional Education and Student Services (BEESS) Resource and Information Center	<ul style="list-style-type: none"> • None • Informational resource for student with developmental disabilities 	<ul style="list-style-type: none"> • Education
Centers for Autism and Related Disabilities (CARD)	<ul style="list-style-type: none"> • Persons of all ages and levels of intellectual functioning who have Autism Spectrum Disorders and related disabilities 	<ul style="list-style-type: none"> • Education • General Assistance • Individual and Family Training
Community Care for the Elderly (CCE) Program	<ul style="list-style-type: none"> • Age 60+ • Functionally impaired as determined by an initial comprehensive assessment and annual reassessments 	<ul style="list-style-type: none"> • Education • Specialist and Primary Care • Medicine and Medical Equipment • Personal and In-Home Supports • General Assistance • Emergency • Individual and Family Training • Food Assistance • Adult Medical • Elderly Support • Transportation • Therapies • Respite
Consumer Directed Care Plus (CDC+)	<ul style="list-style-type: none"> • Must have a developmental disability as defined in Chapter 393 of the Florida Statutes (People severely impaired by Autism, Cerebral palsy, Spina bifida, Intellectual disabilities, Down syndrome, Prader-Willi syndrome, Phelan- 	<ul style="list-style-type: none"> • Medicine and Medical Equipment • Personal and In-Home Supports • Screening and Diagnostic Testing • General Assistance • Housing and Residential Options

Program	Eligibility Criteria	Services Offered
	<p>McDermid syndrome or a child between the age 3-5 who is at a high risk of a developmental disability)</p> <ul style="list-style-type: none"> Disability diagnosed before the age of 18 Enrolled in the iBudget Florida waiver 	<ul style="list-style-type: none"> Dental Individual and Family Training Job Support Transportation Behavioral Therapies Child Medical Adult Medical Elderly Support Therapies Respite Nutrition
Elder Abuse Prevention Program	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> Report Abuse and Fraud Individual and Family Training
Employment Enhancement Project (EEP)	<ul style="list-style-type: none"> 18 years or older Must have a developmental disability as defined in Chapter 393 of the Florida Statutes (People severely impaired by Autism, Cerebral palsy, Spina bifida, Intellectual disabilities, Down syndrome, Prader-Willi syndrome, Phelan-McDermid syndrome or a child between the age 3-5 who is at a high risk of a developmental disability) On the Agency for Persons with Disabilities waiting list for services 	<ul style="list-style-type: none"> Job support
Florida Diagnostic and Learning Resources System (FDLRS)	<ul style="list-style-type: none"> Informational and training site for parents and students with developmental disabilities 	<ul style="list-style-type: none"> Education Individual and Family Training
Florida Early Steps Program	<ul style="list-style-type: none"> Birth to 36 months 	<ul style="list-style-type: none"> Education Specialist and Primary Care

Program	Eligibility Criteria	Services Offered
	<ul style="list-style-type: none"> Physical, cognitive, gross and fine motor skill, communication, social/emotional, or adaptive development delays or established medical conditions Early Steps has a screening process to determine eligibility 	<ul style="list-style-type: none"> Personal and In-Home Supports General Assistance Child Medical Individual and Family Training Blindness and Vision Services Hearing Respite Transportation Therapies Medicine and Medical Equipment Nutrition
Florida Familial Dysautonomia Waiver	<ul style="list-style-type: none"> Have a documented diagnosis of Familial Dysautonomia Be 3 years old or older Be assessed as having an Inpatient Hospital Level of Care (LOC) 	<ul style="list-style-type: none"> Dental Medicine and Medical Equipment Individual and Family Training Behavioral Respite
Florida Healthy Start Program	<ul style="list-style-type: none"> Birth to 3 years Medicaid eligible Department of Health (DOH) funding available to provide services to non-Medicaid eligible population 	<ul style="list-style-type: none"> Education General Assistance Individual and Family Training
Florida Housing: Special Needs Housing Programs	<ul style="list-style-type: none"> Under US Department of Housing and Urban Development (HUD) Homeownership and multifamily developments that participate in the funding programs of Florida Housing Finance Corporation (FHFC) Must meet a variety of income and rent 	<ul style="list-style-type: none"> Housing and Residential Options

Program	Eligibility Criteria	Services Offered
	requirements as determined by the FHFC program used to finance the development	
Florida KidCare: Children's Medical Services	<ul style="list-style-type: none"> • Must meet Medicaid and Florida Healthy Kids financial requirements • Must be the age of 21 or younger • Must meet CMS clinical screening requirements or have a physician attest to child's qualifying medical conditions 	<ul style="list-style-type: none"> • Child Medical • Dental • Hearing • Therapies • Immunizations • Medicine and Medical Equipment • Individual and Family Training • Hospital, Clinic, and Hospice • Screening and Diagnostic Testing • Specialist and Primary Care • Blindness and Vision Services • Transportation
Florida KidCare: Healthy Kids	<ul style="list-style-type: none"> • 5 through 18 years • Ineligible for Medicaid or Children's Medical Services Network • Must be uninsured (you may apply for Healthy Kids while your child has other health insurance, but you must cancel that insurance before Healthy Kids starts) • Must be a U.S. citizen or lawfully residing non-citizen • Not be in a public institution • Determined by Florida Healthy Kids Corp 	<ul style="list-style-type: none"> • Education • Specialist and Primary Care • Hospital, Clinic, and Hospice • Medicine and Medical Equipment • Personal and In-Home Supports • Screening and Diagnostic Testing • Immunizations • Dental • Blindness and Vision Services • Home Care • Child Medical • Individual and Family Training • Behavioral

Program	Eligibility Criteria	Services Offered
Florida KidCare: Medicaid for Children	<ul style="list-style-type: none"> • Birth – 20 years • Must meet income eligibility requirements determined through the Department of Children and Families or Social Security Administration (if eligible for Supplemental Security Income) • Services may be provided through the fee-for-service delivery system or through a health plan (managed care) 	<ul style="list-style-type: none"> • Education • Specialist and Primary Care • Hospital, Clinic, and Hospice • Medicine and Medical Equipment • Personal and In-Home Supports • Screening and Diagnostic Testing • Immunizations • Dental • Blindness and Vision Services • Individual and Family Training • Therapies • Behavioral • Hearing • Child Medical
Florida KidCare: MediKids	<ul style="list-style-type: none"> • Age 1 through 4 years • Ineligible for Medicaid or Children's Medical Services Network • Must be uninsured (you may apply for MediKid while your child has other health insurance, but you must cancel that insurance before MediKid starts) • Must be a U.S. citizen or lawfully residing non-citizen • Not be in a public institution • Determined by Florida Healthy Kids Corp 	<ul style="list-style-type: none"> • Blindness and Vision Services • Child Medical • Dental • Hearing • Transportation • Hospital, Clinic, and Hospice • Medicine and Medical Equipment • Personal and In-Home Supports • Therapies • Specialist and Primary Care • Screening and Diagnostic Testing
Florida Medicaid	<ul style="list-style-type: none"> • 21 years and older • Must meet income eligibility requirements determined through the 	<ul style="list-style-type: none"> • Education • Specialist and Primary Care • Hospital, Clinic, and Hospice

Program	Eligibility Criteria	Services Offered
	<p>Department of Children and Families or Social Security Administration (if eligible for Supplemental Security Income)</p> <ul style="list-style-type: none"> Services may be provided through the fee-for-service delivery system or through a health plan (managed care) 	<ul style="list-style-type: none"> Medicine and Medical Equipment Personal and In-Home Supports Screening and Diagnostic Testing General Assistance Housing and Residential Options Emergency Immunizations Dental Blindness and Vision Services Home Care Adult Medical Individual and Family Training Transportation, Behavioral Therapies Hearing Elderly Support
Florida Voluntary Prekindergarten (VPK) Specialized Instructional Services Education Program	<ul style="list-style-type: none"> Must first be enrolled through local early learning coalition office Child must live in Florida Child must be 4 years old on or before Sept. 1 of the current year Child must have a current IEP from local school district 	<ul style="list-style-type: none"> Education Behavioral Therapies
iBudget Florida (Home and Community Based Waiver)	<ul style="list-style-type: none"> Must have a developmental disability as defined in Chapter 393 of the Florida Statutes (People severely impaired by Autism, Cerebral palsy, Spina bifida, Intellectual disabilities, Down syndrome, Prader- 	<ul style="list-style-type: none"> Education Medicine and Medical Equipment Personal and In-Home Supports Screening and Diagnostic Testing General Assistance

Program	Eligibility Criteria	Services Offered
	<p>Willi syndrome, Phelan-McDermid syndrome or a child between the age 3-5 who is at a high risk of a developmental disability)</p> <ul style="list-style-type: none"> Disability diagnosed before the age of 18 	<ul style="list-style-type: none"> Housing and Residential Options Dental Home Care Individual and Family Training Job Support Transportation Behavioral Therapies Adult Medical Elderly Support Child Medical Adult Medical Respite Nutrition
<p>Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)</p>	<ul style="list-style-type: none"> Developmental disability is a disorder or syndrome that is attributable to: <ul style="list-style-type: none"> intellectual disabilities, Cerebral palsy, Autism, Spina bifida, or Prader-Willi syndrome that manifests before the age of 18 and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely Have the level of need and level of reimbursement determined by the Agency 	<ul style="list-style-type: none"> Housing and Residential Options Nutrition Dental Medicine and Medical Equipment Adult Medical Specialist and Primary Care

Program	Eligibility Criteria	Services Offered
	<p>for Persons with Disabilities (APD) in the last six months</p> <ul style="list-style-type: none"> • Meet the requirements for the Institutional Care Program 	
Long-Term Care (LTC) Managed Care Program	<ul style="list-style-type: none"> • Age 65+ and eligible for Medicaid • Age 18+ and eligible for Medicaid by reason of a disability • Be determined by the Comprehensive Assessment and Review for Long-Term Care Services (CARES) unit at the Department of Elder Affairs to be at nursing home level of care and meet one or more established clinical criteria 	<ul style="list-style-type: none"> • Education • Specialist and Primary Care • Hospital, Clinic, and Hospice • Medicine and Medical Equipment • Personal and In-Home Supports • General Assistance • Housing and Residential Options • Emergency • Elderly Support • Home Care
Medicaid Certified School Match (MCSM) Program	<ul style="list-style-type: none"> • Under the age of 21 • Medicaid eligible • In a school district that is part of the public education system. Also, charter schools and lab schools (also known as developmental research schools) can participate in the program if their contracts with their school districts indicate such • Has an IEP or FSP 	<ul style="list-style-type: none"> • General Assistance • Immunizations • Blindness and Vision Services • Child Medical • Job Support • Hearing • Therapies • Transportation • Behavioral • Education
Program of All-Inclusive Care for the Elderly (PACE)	<ul style="list-style-type: none"> • Age 55+ • Live within the defined service area of the PACE Center • Meet medical eligibility requirements as determined by CARES 	<ul style="list-style-type: none"> • Specialist and Primary Care • General Assistance • Elderly Support • Adult Medical • Personal and In-Home Supports

Program	Eligibility Criteria	Services Offered
	<ul style="list-style-type: none"> • Be able to safely live in the community • Be dually eligible for Medicaid and Medicare, or Medicaid only 	
Vocational Rehabilitation (VR)	<ul style="list-style-type: none"> • Individuals 15+ not in school • With one or more disabilities that present barriers to getting or keeping a job • Individuals want to work and • Need VR services to achieve this goal 	<ul style="list-style-type: none"> • Education • Individual and Family Training • Job Support
Vocational Rehabilitation (VR) Transition/ Youth Services	<ul style="list-style-type: none"> • Students 15 – 21 who are in school • Students who have a 504 Plan • Students who have an Individual Educational Plan (IEP) • Other students with disabilities 	<ul style="list-style-type: none"> • Education • Specialist and Primary Care • Screening and Diagnostic Testing • General Assistance • Individual and Family Training • Job Support

Source: Florida Agency for Persons with Disabilities, n.d.

BARRIERS FOR UNSERVED AND UNDERSERVED PERSONS WITH I/DD

This assessment used multiple approaches to uncover and identify unserved and underserved populations in Florida. In the secondary data collection and analysis process, whenever possible indicators that could be aggregated by age, gender, race and ethnicity were used. In addition, geographic sorting, by county and by FDDC service region, was conducted to identify differences by location and rural and urban settings. Poverty was another secondary data filter that was applied when feasible to spotlight any populations showing higher risks for negative outcomes and/or barriers to resources. The public input phase of the assessment process collected primary data through key informant interviews, surveys of self-advocates and their caregivers and family members and focus group discussions with several groups, including advocates from Partners in Policymaking (PIP), self-

advocates, and the aging caregivers of persons with I/DD. As reported earlier, both surveys were available in Spanish and promoted and distributed statewide to Spanish-speaking groups. All three of the primary data collection methods incorporated questions to better understand: gaps in services, unmet needs of persons with I/DD and their families and caregivers, barriers to filling those needs, and which, if any, groups or populations experience greater needs and/or impediments in getting the services and supports they need. These secondary and primary data results were shared and reviewed with FDDC Council members at their regular meeting in May 2020. Council members examined assessment data and findings to identify where data pointed to common themes, converged on related issues and populations, and diverged or pointed to the need for further investigation. Using a facilitated consensus discussion process, Council members cataloged themes and issues of strategic importance and noted groups that merit focused interventions.

Three populations were identified as being unserved or underserved: aging caregivers for persons with I/DD, those with I/DD residing in rural areas of Florida and their families and caregivers, and persons with I/DD who have maladaptive behaviors and/or mental illness (dual diagnosis).

AGING CAREGIVERS FOR PERSONS WITH I/DD

Secondary data show that more than 20 percent of Florida's population is 65 years of age or older (Demographics Table 5, Technical Appendix). In the super senior age group (those 80 years and older), since 1970 Florida's population has seen increases of 77.6 percent in the 80 to 84 years of age group. The 80 to 84 years of age group represented 2.5 percent of Florida's total population in 2018 and an increase of more than 300.0 percent in the 85 years and older age group to reach the 2018 proportion of the population at 2.6 percent (Florida Department of Health, 2020). From 2016-2018, the numbers of adults 18 years of age and older with I/DD have increased by about 2.0 percent each year (Demographics Table 11, Technical Appendix). As noted earlier, the documented prevalence of I/DD in Florida is conservative and likely an underestimate. In Florida, at the highest percentage in the U.S., about 33.0 percent of those living with family caregivers live with aging caregivers aged 60 years and older (Perkins, 2019). Public input data clearly pointed to aging caregivers as a special population. Focus groups articulated concerns for aging self-advocates as well as the family members who care for them. Almost 50.0 percent of caregiver/family survey respondents said among their highest concerns were fatigue, stress, and burnout, and worrying about the future, while more than one-third were concerned about financial issues. Another 20.0 percent cited managing other family responsibilities and their own physical health as top concerns. Resource needs for aging caregivers were also reported by these survey respondents. Almost 30.0 percent said they need respite care. About one-quarter need resources to meet the healthcare needs of the person in their care, local community-based services,

and daily caregiving task assistance. Nearly 20.0 percent cited aging caregiver support as a top need (FDDC Caregiver/Family Survey, 2020).

PERSONS WITH I/DD RESIDING IN RURAL AREAS

According to the latest U.S. Census estimates, Florida's 32 rural counties are home to about 1.1 million people. About 18,041 persons with I/DD live in rural Florida. Data show that Florida's rural population faces challenges with poverty, as a greater percentage live below the poverty level (16.4 percent) compared to Florida's urban counties (13.1 percent) (Demographics Table 8, Technical Appendix). Florida's rural population is older, with 21.3 percent of the population at 65 years of age or older compared to 19.6 percent in urban areas (Demographics Table 6, Technical Appendix). The 2020 County Health Rankings scored 16 of Florida's rural counties in the bottom quartile for the quality of health outcomes and health factors when compared and ranked with all Florida counties. None of Florida's rural counties ranked among the top ten in the annual rankings (Health Table 1, Technical Appendix). While these rankings do not specifically look at population disability factors, they provide an overarching look at the health and social environment and resources available to all persons. Public input pointed to challenges and barriers faced by persons with I/DD who live in rural areas. Focus group participants voiced concerns about the overall lack of access to services and supports linked to the limited providers and organizations that provide community-based services. Transportation was raised as a persistent issue, although noted to be a problem in both rural and urban areas. Information access, particularly in areas where Internet service is limited, was also raised as a barrier. Key Informant Interview participants equally expressed concerns for meeting the needs of rural Floridians in effective and cost-efficient ways.

PERSONS WITH I/DD WHO HAVE A DUAL DIAGNOSIS (I/DD AND MENTAL ILLNESS, AND SEVERE OR MALADAPTIVE BEHAVIORS)

According to the Agency for Persons with Disabilities, rates of Baker Acts for persons with I/DD is highest among persons who receive Behavior Scores 5 and 6 on the QSI. In calendar years 2015 – 2020, there were 66,781 APD consumers. Of those consumers, 22,227 had Behavior Scores 5 or 6 and 44,554 had Behavior Scores of 4 and below. In total, 2,870 APD consumers were Baker Acted. Even though persons with I/DD with Behavior Scores of 5 and 6 only represent 33 percent of APD consumers, they represent 80.55 percent of Baker Acts (Addendum Tables 1 and 2, Technical Appendix). In other words, persons with I/DD who receive high Behavior Scores on the QSI may be in need of additional services related to maladaptive behaviors. The Agency for Persons with Disabilities does not serve all Florida residents with I/DD. It is estimated that there are approximately 336,529 people living with I/DD in Florida, indicating the number of persons with I/DD who were Baker Acted from 2015 – 2020 could be much higher (Addendum Table 2, Technical Appendix).

Concerns for persons with I/DD and a dual diagnosis was discussed by two focus groups: Partners in Policymaking and the aging caregivers focus group. According to focus group participants, persons with I/DD and maladaptive behaviors or mental illness (dual diagnosis), may exhibit disruptive behaviors that may be misunderstood by law enforcement leading to restraint and seclusion or restrictive settings. Furthermore, focus group participants discussed the need for additional services for this I/DD population expressing concerns that managing significant behavioral challenges requires many services and supports throughout the lifespan.

TABLE 23. KEY ISSUES IDENTIFIED AND SOURCE ASSESSMENT, 2020

Key Issues Identified	Source Assessment						
	TA	Focus Groups			Surveys		
		PIP	Self-Advocates	Aging Caregivers	Self-Advocate	Caregiver/Family Member	Key Informant Interviews
Access to services	X	X	X	X	X	X	X
Accountability of agencies for financial resources	X						X
Aging caregivers	X	X	X	X		X	X
Caregiver fatigue				X		X	X
Community support services (services that keep persons with IDD in the home, community)	X	X	X	X	X	X	
Dual diagnosis (I/DD and mental health, and severe or maladaptive behaviors)	X			X		X	X
Education system challenges	X	X	X		X	X	
Emerging issues (emergency response, pandemic)							X

Key Issues Identified	Source Assessment						
	TA	Focus Groups			Surveys		
		PIP	Self-Advocates	Aging Caregivers	Self-Advocate	Caregiver/Family Member	Key Informant Interviews
response, telehealth)							
Employment and job training	X	X	X		X		
Financial burdens of self-advocates, caregivers, family	X	X	X	X		X	X
Funding for agencies to provide services, supports	X	X	X				
Housing (affordability, issues related to independence and institutionalization	X		X	X	X	X	X
iBudget preservation	X	X	X		X		X
Managed care and service delivery systems including Medicaid	X	X	X	X			X
Mistreatment, bias, discrimination perpetuated in systems and practices		X	X				
Post-secondary transition	X	X	X		X	X	X
Providers (lack of professionals to provide health care, social and community support services)	X	X	X	X	X	X	X

Key Issues Identified	Source Assessment						
	TA	Focus Groups			Surveys		
		PIP	Self-Advocates	Aging Caregivers	Self-Advocate	Caregiver/Family Member	Key Informant Interviews
Recreational opportunities	X				X		
Rights of self-advocates, caregivers		X			X		
Service quality, uniformity, continuity (applies to both health care and community support services)	X	X	X	X	X	x	
Social acceptance and support (ability to fully participate in social networks and society)		X	X		X		
System complexity	X	X	X	X		X	X
Transportation	X	X	X		X		X
Wait list	X	X	X	X	X	X	X

Note: X = theme identified in assessment findings; TA = Technical Appendix, PIP = Partners in Policymaking,

Source: FDDC Comprehensive Review and Analysis, 2020, prepared by WellFlorida Council, 2021

AVAILABILITY OF ASSISTIVE TECHNOLOGY

Assistive technology services and devices are available to Floridians through several means. The Florida Alliance for Assistive Services and Technology, Inc. (FAAST) is a nonprofit organization funded through the Assistive Technology Act of 2004 and the Florida general revenue funds under Florida Statute 413.407. The Florida Department of Education, Division of Vocational Rehabilitation is FAAST's sponsor. FAAST's mission focuses on improving the quality of life for all Floridians with disabilities through increasing access to assistive services and technology. Core services include assistive technology (AT) device loan programs, AT device refurbishing and recycling programs, AT device exchange, skills development and transition trainings, AT device demonstrations, AT information and technical

assistance, and the New Horizon Loan Program. The device loan program allows customers to try out devices at home to ascertain if such devices are a match for their specific needs. FFAST device demonstrations start with a personalized AT assessment to make recommendations that suit the user, their needs, and budget. Information services include a help desk, blog, classified section, and website. FFAST offers trainings in group settings and focuses on information technology and telecom technology as well as the application of AT in transitions, including postsecondary, workplace, and aging. The New Horizon Loan program is a finance program to provide assistance to persons with disabilities with purchasing AT at reasonable interest rates; in 2019, the program made 40 such loans. There are six regional demonstration centers (RDC) that offer FFAST services locally. Sites include the Atlantic RDC at the University of Central Florida in Orlando, Central Florida RDC at Tampa General Hospital Rehabilitation Center in Tampa, Gulf Coast RDC at the Center for Independent Living Disability Resource Center in Pensacola, Northeast RDC at Hope Haven Children's Clinic in Jacksonville, Northwest RDC at The Family Café in Tallahassee, and the South Florida RDC at the University of Miami Mailman Center in Miami. In 2019, 97.5 percent of FFAST customers rated their satisfaction with services as satisfied or highly satisfied. During that same time period, about 470 devices were exchanged, netting customers combined savings of nearly \$ 70,000. Device refurbishments numbered nearly 1,300, resulting in combined net savings for consumers of more than \$250,000. FFAST's 1,087 demonstrations reached more than 3,300 individuals, and 13,334 participants benefited from trainings. FFAST trainings were concentrated in Florida's metropolitan areas, where 78.0 percent of trainings took place (Assistive Technology Tables 1-6, Technical Appendix).

As part of their mission to "help people with disabilities find and maintain employment and enhance their independence," the Florida Department of Education (DOE) Division of Vocational Rehabilitation (VR) provides AT for community and independent living, workplaces, and education settings. Types of AT that VR can provide include vehicle modifications, customized mobility devices aids, such as wheelchairs and scooters, worksite accommodations, and adaptive equipment. In 2019, VR invested 9.0 percent of its client services expenditures on AT (Florida Department of Education, Division of Vocational Rehabilitation, 2019).

Florida DOE Bureau of Exceptional Education and Student Services (BEESS) assures that students with disabilities have access to assistive technology devices and accompanying services. Services include needs assessments, procurement of appropriate assistive technology, designing and adapting equipment, training on equipment use, maintenance, and coordination of use with other services. Assistive devices come in a range, from low technology (e.g., pencil grips, tactile rules, light pens, page holders, visual supports that increase independent functioning), mid-level technology (e.g., timers, digital recorders, calculators, switch-operated appliances, and communication systems), and complex

technology (e.g., computers, mobile devices, alternative keyboards, graphic, and text-to-speech software) (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2013).

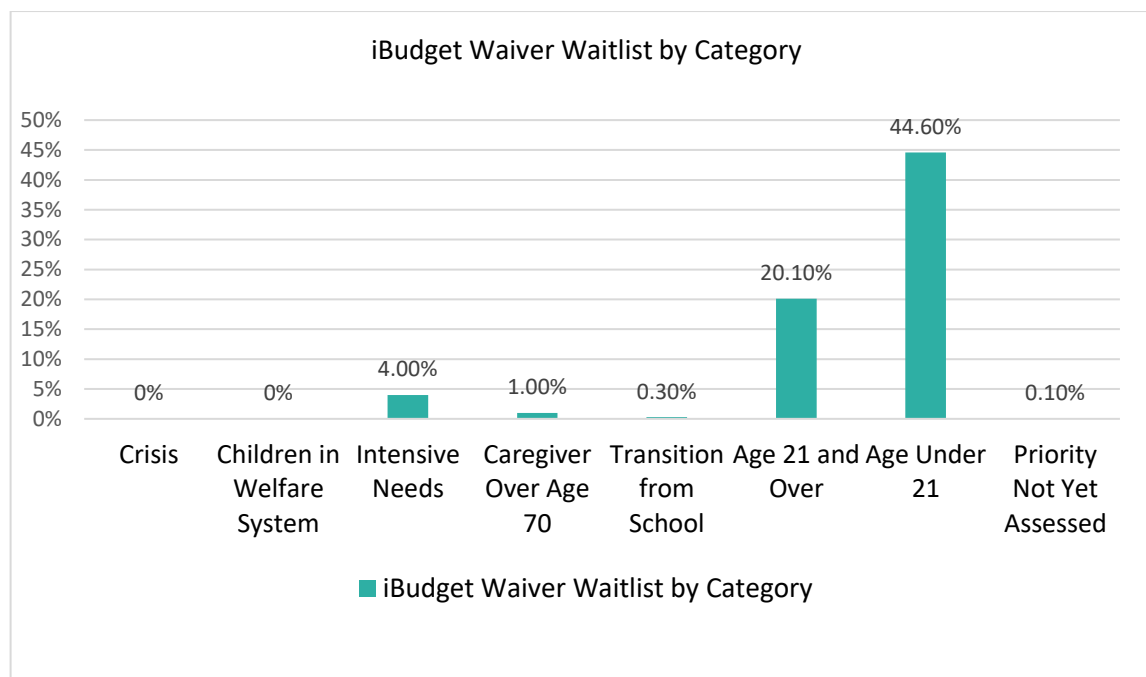
Another DOE program, Florida Diagnostic and Learning Resources System (FDLRS), offers services for the appropriate use of numerous technologies for students, teachers, professional staff and parents. Technology specialists at the 19 FDLRS centers throughout the state provide support in the areas of assistive technology, instructional technology, Universal Design for Learning (UDL), Accessible Instructional Materials/National Instructional Materials Accessibility Standards (AIM/NIMAS) services, and virtual/online instruction. Through FDLRS, students and teachers have access to a statewide assistive technology loan library.

Persons with I/DD may have access to AT services through Medicaid and the iBudget Florida Home and Community-Based Services Waiver. The AT options that may be available include: ambulatory aids, vehicle adaptation, wheelchairs, carriers, and lifts. Home technologies could include adaptive switches for equipment operation, doors locks and openers, and communication devices.

WAITING LISTS

A major issue for the iBudget is the lack of fiscal support it receives from the Florida legislature, causing many individuals to be placed on a waitlist until they are able to receive services. Approximately 60 percent of persons receive services, while 40 percent are on the waitlist (Agency for Persons with Disabilities, 2020). As of February 2020, the waitlist has 22,865 persons on it, where the total of all individuals waiting for services are separated into categories to assess the highest need clients first (Informal and Formal Services and Supports 23, Technical Appendix). Individuals deemed to be in “crisis” receive priority.

FIGURE 27. IBUDGET WAIVER WAITLIST BY CATEGORY, BY PERCENT, FLORIDA, 2020



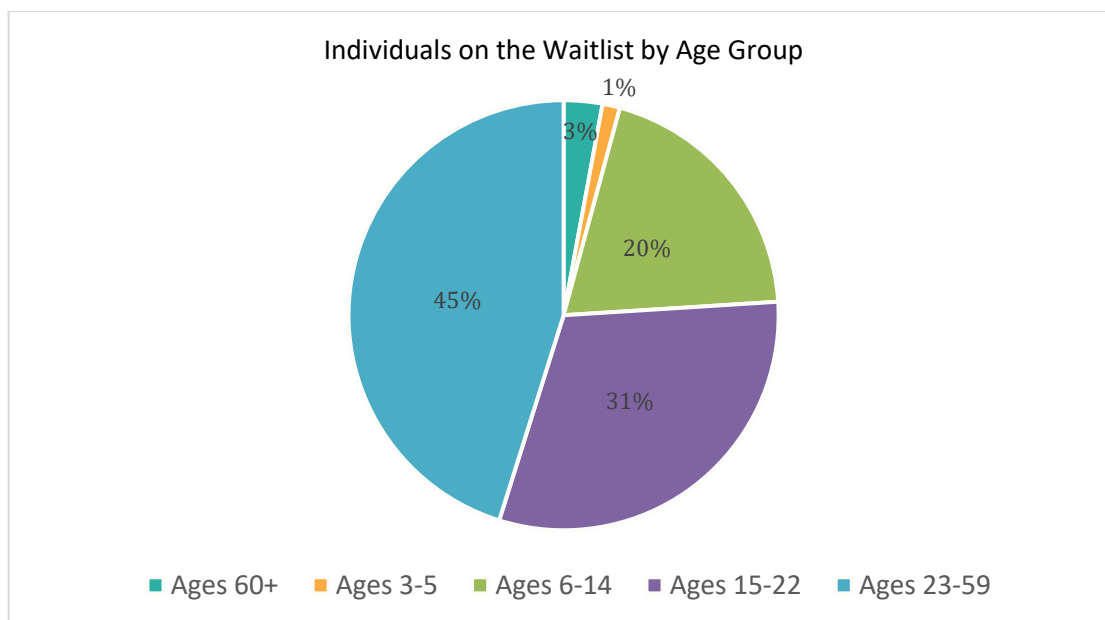
Note: Individuals in "crisis" receive priority

Source: University of South Florida, Florida Center for Inclusive Communities, 2021

Compared to the United States, Florida has the highest percentage of persons on a waiting list living with aging caregivers. An aging caregiver is defined as an individual over the age of 60 who is caring for their adult child. Because of this, there are impacts to the overall family unit, as caregivers must wait until they reach age 70 for their aging, adult children to receive iBudget services.

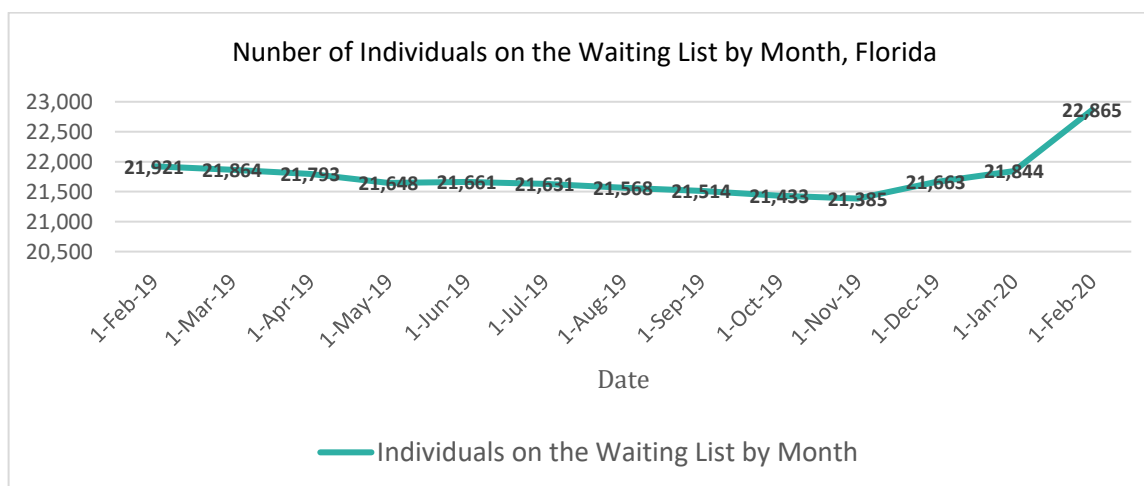
Florida ranks 49th out of 50 states in "fiscal effort" or I/DD funding. As a comparison, New York, which is ranked 1st out of 50 states, spends \$9.06 per \$1,000 of personal income; Florida spends \$1.99 per \$1,000 of personal income (Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021). Additionally, Florida's overall fiscal effort has decreased by approximately 10 percent since 2007 (Perkins, 2019).

FIGURE 28. INDIVIDUALS ON WAITLIST BY AGE GROUP, BY PERCENT, FLORIDA, 2020



Source: University of South Florida, Florida Center for Inclusive Communities, 2021

FIGURE 29. NUMBER OF INDIVIDUALS ON WAITLIST BY MONTH, FLORIDA, FEBRUARY 2019-2020



Source: University of South Florida, Florida Center for Inclusive Communities, 2021

ANALYSIS OF ADEQUACY OF CURRENT RESOURCES AND PROJECTED AVAILABILITY

At the time of this assessment, Florida, the United States, and the world are in the midst of the response to a global coronavirus pandemic and in various stages of recovery in citizens' health, healthcare, and social system resource availability, as well as economic impact. In Florida, the current unemployment rate in April 2020 rose to nearly 13.0 percent from the February rate of 2.3 percent. March sales tax revenues were more than \$770 million less than planned with April losses expected to be larger. Medicaid enrollments are surging and predictions of up to one billion dollars in additional Medicaid spending are reported (Sexton, C. News Service of Florida, 2020) Florida's Fiscal Year 2020-2021 budget of \$92.2 Billion, was signed into law on June 29, 2020 (Governor Ron DeSantis Staff, 2020). The analysis that follows uses fiscal projections made before the pandemic. Many of these projections will likely change; however, for planning purposes, the following information provides a history and baseline for projections.

According to Florida's three-year fiscal outlook for fiscal years 2020-2021 through 2022-2023, prepared jointly by The Senate Committee on Appropriations, The House Appropriations Committee, and The Legislative Office of Economic and Demographic Research, Florida will need an additional \$6.18 billion in general revenue over those three years to cover services in ten policy areas. As shown in the table below, general revenue needs in prekindergarten through 12 education, as well as human services, are predicted to increase to 18.5 percent and 22.9 percent, respectively, of overall general revenue spending. Many of the services vital to persons with I/DD are financed through these policy areas. Specific to the Agency for Persons with Disabilities, a projected increase of \$22.4 million in general revenue will be needed each for each of these three fiscal years, in an effort to finance the following: a reduction of the waitlist for services for persons with I/DD, administrative service to manage growth in the iBudget Florida Waiver services, supported employment and internship programs, and rate increases for Medicaid Waiver providers.

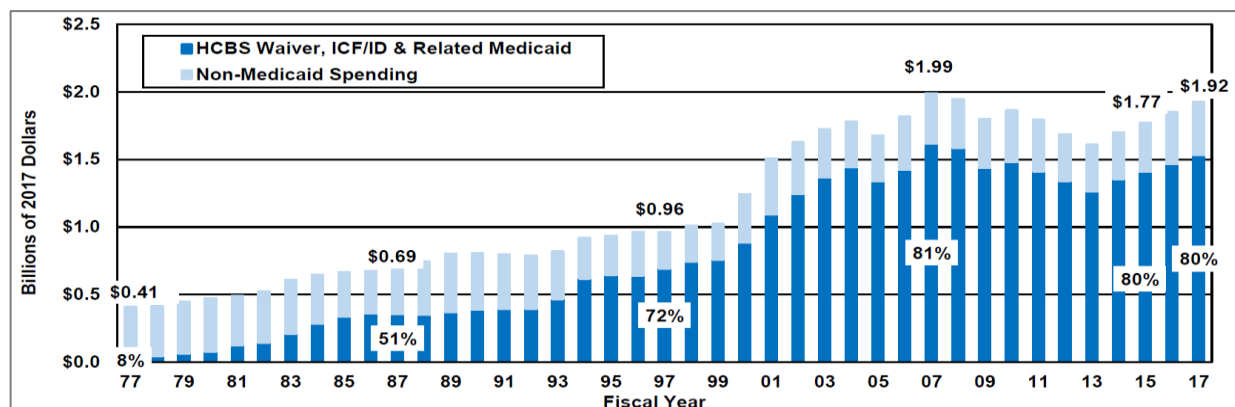
TABLE 24. GENERAL REVENUE FUND PERCENTAGE OF TOTAL CRITICAL AND OTHER HIGH PRIORITY NEEDS BY POLICY AREA FOR 2020-2021 – 2022-2023, STATE OF FLORIDA, SEPTEMBER 2019

Policy Area	Fiscal Year - Percentage		
	2020-2021	2021-2022	2022-2023
PreK-12 Education	7.9	16.5	18.5
Higher Education	8.5	7.0	8.6
Education Fixed Capital Outlay	1.2	1.4	0
Human Services	19.0	28.5	22.9
Criminal Justice	5.6	4.0	4.9
Judicial Branch	0.1	0.1	0.1
Transportation and Economic Development	24.7	16.7	14.3
Natural Resources	15.8	11.5	13.6
General Government	5.5	4.0	3.8
Administered Funds – Statewide Issues	11.6	10.3	13.4

Source: The Legislative Office of Economic and Demographic Research, 2019

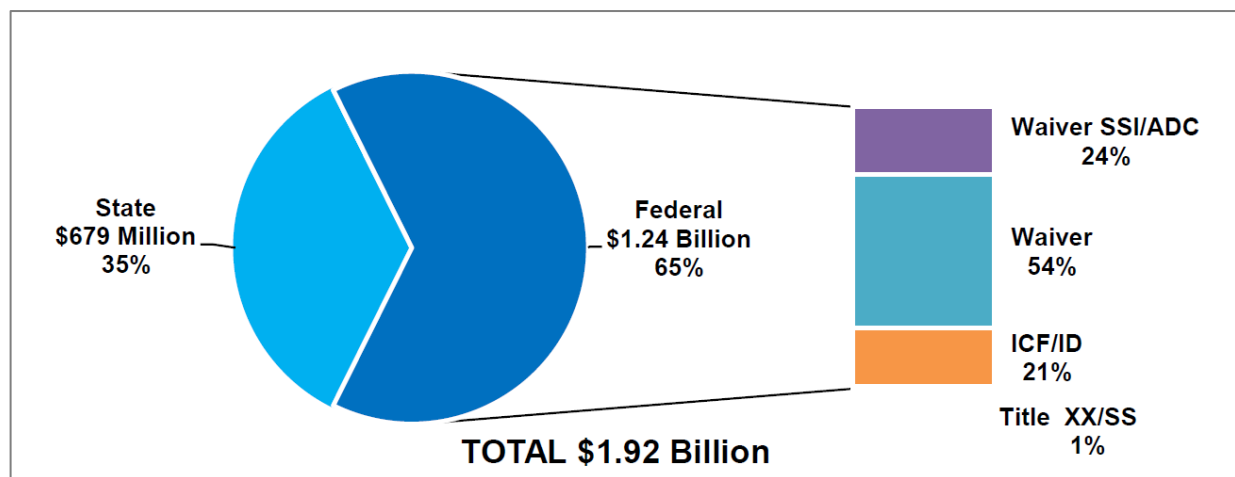
As can be seen in the three figures that follow, Florida's total spending for intellectual and developmental disability spending has risen. The comparative proportions of non-Medicaid spending and Home and Community-based Services (HCBS) Waiver, Intermediate Care Facility for Persons with Intellectual Disabilities and related Medicaid spending have remained relatively static since 2001 when those proportions reached 20 percent and 80 percent, respectively (Tanis, E.S., Lulinski, A., Wu, A., Braddock, D., and Hemp, R., 2021). The sources for public spending for intellectual and developmental disability services in Florida are 35 percent state funded and 65 percent federally funded. Trends in fiscal efforts for community and institutional spending for intellectual and developmental disability services show a divergence since the year 2000 with spending on institutional services falling and community service spending increasing exponentially based on dollars spent per \$1,000 personal income (Tanis, E.S., Lulinski, A., Wu, A., Braddock, D., and Hemp, R., 2021).

FIGURE 30. TOTAL PUBLIC SPENDING FOR INTELLECTUAL AND DEVELOPMENTAL DISABILITY SERVICES, FLORIDA, FISCAL YEAR 1977 - 2017



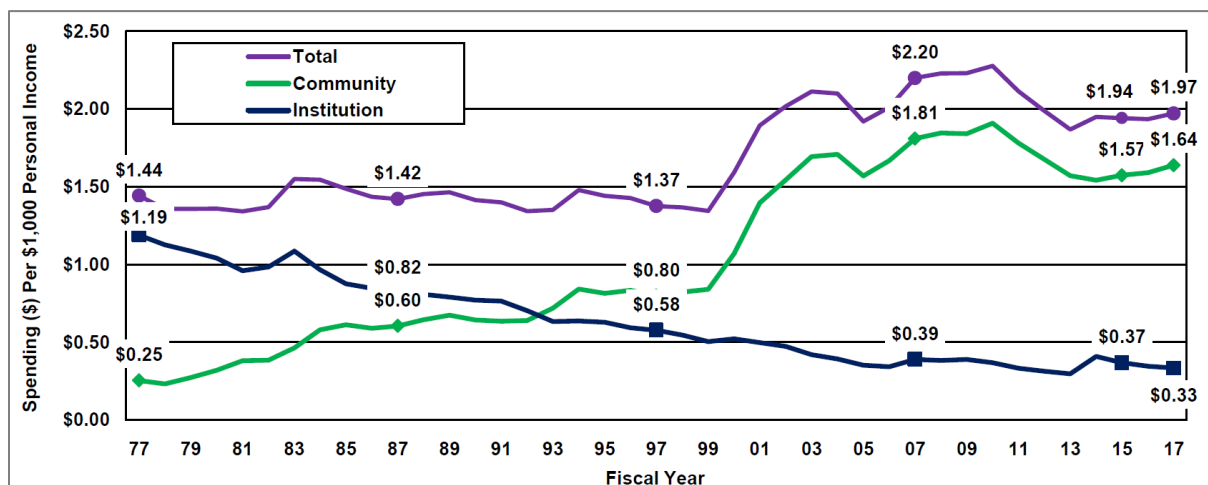
Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 31. PUBLIC SPENDING FOR INTELLECTUAL AND DEVELOPMENTAL DISABILITY SERVICES BY REVENUE SOURCE, FLORIDA, FISCAL YEAR 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 32. FISCAL EFFORT FOR INTELLECTUAL AND DEVELOPMENTAL DISABILITY SERVICES, FLORIDA, FISCAL YEARS 1977 - 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

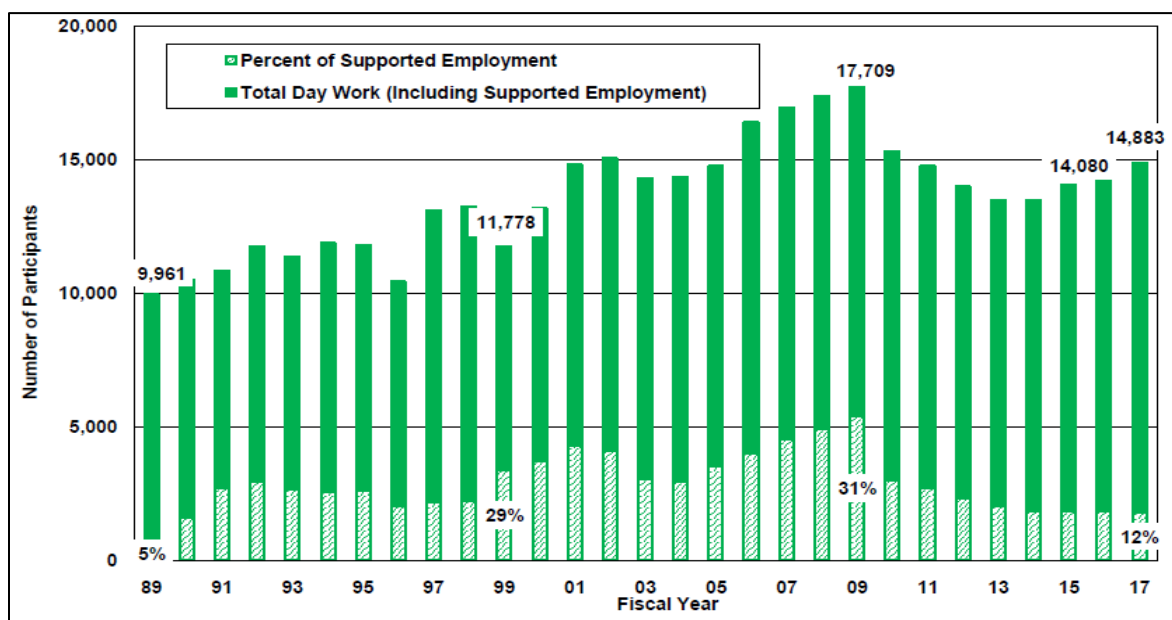
As described previously, special education and education services for school-aged children from three (3) to 21 year are provided the Florida Department of Education, Bureau of Exceptional Education and Student Services (BEES) supported by Individuals with Disabilities Act (IDEA) Part B funding. There were 349,764 students aged 6 through 21 years who received Part B services in Florida schools during academic year 2017-2018. According to the 2019 State Education Agency (SEA) Profile, there were 2,846,857 students in Florida's pre-kindergarten through 12th grade population, of which 14.0 percent, or 401,745, were students with disabilities. Students with intellectual disabilities represent about 7.1 percent of all students with disabilities; that is, students with intellectual disabilities numbered 28,523 in 2019 (Florida Department of Education, Bureau of Exceptional Education and Student Services, 2019). According to the Florida Department of Education's State Report Card, total costs per student for the 2019-2020 school year were \$8,859 (Florida Department of Education, 2020). Sources of funding for school districts in 2018-2019 were 39.9 percent from state sources, about 48.8 percent from local sources, and 11.3 percent from federal sources. Program cost factors are used to assure an equitable distribution of funds in relation to relative costs per student. Basic program cost factor weights for Kindergarten and grades 1, 2 and 3 (cost factor weight 1.124) are the same as for programs for exceptional student education, and this holds true for basic programs and grades 4, 5, 6, 7 and 8 with exceptional student education services (cost factor weight 1.000) as well as grades 9, 10, 11 and 12 with exceptional student education services (cost factor weight 1.012). Program for exceptional student education at support levels 4 (cost factor weight 3.644) and 5 (5.462) reflect a cost investment

for these students (Florida Department of Education, n.d.). Florida Department of Education's federal fiscal year 2021 annual state application for IDEA Part B funding shows state fiscal year 2019 state financial support for special education and related services for students with disabilities at 1.002 billion dollars or \$2,471.43 per student receiving these services. Small increases were reported for the 2020 state fiscal year at 1.073 billion dollars and \$2,552.38 per student (Florida Department of Education, 2021). The Special Education Expenditure Project report found that nationally per pupil education expenditures vary by disability category and that spending per student is about 1.9 times higher for those who receive special education services (Center for Special Education Finance, 2003),

Numerous agencies dedicate their work to helping assure that persons with disabilities, including I/DD, have opportunities to train, find employment, and get the services and supports to enhance employment prospects. The Florida Department of Education Division of Vocational Rehabilitation (VR) is a leader in our state. VR lists among its programs and services the Transition Youth Program to help students prepare and plan for post-high school employment; Deaf, Hard of Hearing, and Deaf-Blind Services that include training for both the employee and employer; Supported Employment services that aim to assist those with the most significant disabilities be successful in competitive employment; Independent Living Program services through a statewide network of locally-based Centers for Independent Living (CILs); and the Florida Alliance for Assistive Services and Technology (FAAST) which provides assistive technology devices and services so that persons with disabilities can fully participate in independent living, education, work, and recreation through their lives. Other agencies that support employment opportunities for persons with I/DD include the Florida Division of Blind Services, Florida's 24 Local Workforce Development Boards through the state's Department of Economic Development, The Able Trust, and Florida Association of Rehabilitation Facilities (ARF) that manages the RESPECT of Florida program.

According to the *National Report on Employment Services and Outcomes*, (Winsor, 2019), in Florida about 23.5 percent of working-age persons with a cognitive disability are employed, compared to 33.3 percent of those with any disability, and 73.2 percent of persons with no disability. Employment outcomes for working-age Floridians show that the percentage of persons with no disability living below the poverty line in 2017 was 12.0 percent, 25.4 percent for persons with any disability, and highest for persons with a cognitive disability at 28.3 percent. VR reports in 2017 that the average number of days from eligibility to case closure into employment for persons with I/DD was 689 days with 29.2 percent of closures for persons with I/DD resulting in employment (Winsor, 2019). As shown below, the percent of supported employment for persons with I/DD is at low of 12 percent with the numbers of participants down noticeably (Tanis, E.S., Lulinski, A., Wu, A., Braddock, D., and Hemp, R., 2021).

FIGURE 33. TOTAL DAY/WORK AND SUPPORTED EMPLOYMENT PARTICIPANTS, FISCAL YEARS 1989 - 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

Data from the National Core Indicators (NCI) survey of persons with I/DD in Florida point to continuing challenges with transportation barriers not only for accessing essential services but also in connection with staying in contact with friends and socializing. For example, 47 percent of NCI survey respondents said lack of transportation was a barrier to seeing friends as compared to 38 percent nationally. Lack of transportation was the biggest barrier, outscoring money, time, support staff, and rules or regulations. Only 20 percent of persons with I/DD who responded to the NCI survey reported having attended a self-advocacy meeting or event and about 36 percent report having voted in a local or national election (National Core Indicators, 2019).

Focus group participants, key informants, and survey respondents expressed concerns related to the availability and accessibility of resources. Most notably, concerns related to the iBudget Waiver and waitlist were themes present in all public input opportunities. Concerns related to services and resources for transportation, education, employment, housing and recreation were also common themes. Overall, there is an abundance of need, but limited resources to meet all the needs of the I/DD population.

Florida's fiscal resources to support persons with I/DD in finding services and supports have historically been among the lowest in the nation with a decrease in fiscal effort of about 10 percent since 2007 (Perkins, 2019). Population growth compounds funding inadequacy as Florida's population expands in numbers and diversity. 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.

ANALYSIS OF ADEQUACY OF HEALTHCARE AND OTHER SERVICES, SUPPORTS AND ASSISTANCE FOR PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES WHO ARE IN FACILITIES

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) deliver rehabilitative and health services to persons with I/DD in protected, residential settings. Need of and receipt of active treatment, which consists of ongoing, consistent, specialized and generic training, treatment, and health services, is a requirement for Medicaid coverage for ICF/IID care. Eligibility for Florida Medicaid recipients requiring ICF/IID services is determined by Florida's Agency for Persons with Disabilities (APD). ICF/IIDs are designed to provide the highest levels of support and interventions for persons with I/DD paid for using federal dollars. According to the Florida Association of Rehabilitation Facilities (Florida ARF), there are 87 ICF/IIDs in Florida with a total of 2,071 licensed beds. The occupancy rate for ICF/IIDs is approximately 95 percent. In Florida the number of ICF/IIDs beds is currently frozen by a licensure moratorium. Florida's ICF/IIDs include 38 six- (6) bed homes, 27 cluster facilities, six (6) 64-bed campuses, and 16 other facilities with variations of these models. Six-bed homes are located in residential areas with operations similar to group homes where residents can be involved in community activities. Clusters are comprised of three (3) homes located close together but operating as separate living units. Four (4) semi-private rooms make up each home. Clusters tend to specialize in serving medically fragile persons with I/DD and provide extensive medical and rehabilitative services. Four (4) separate living units each with eight (8) semi-private rooms make up the 64-bed campus model where residents can be active in day programs and community activities (Florida Association of Rehabilitative Facilities, n.d.).

Over the past 50 years, shifts in scientific research, public awareness, policy and legislative changes and strong self-advocacy from persons with I/DD and their families spurred institutional reform and significant growth in community living for persons with I/DD. Nationally, about 75 percent of adults with I/DD live with parents or other family members, with the majority not receiving any formal services or supports (Friedman, 2019). This growing shift in Florida was described earlier and can be

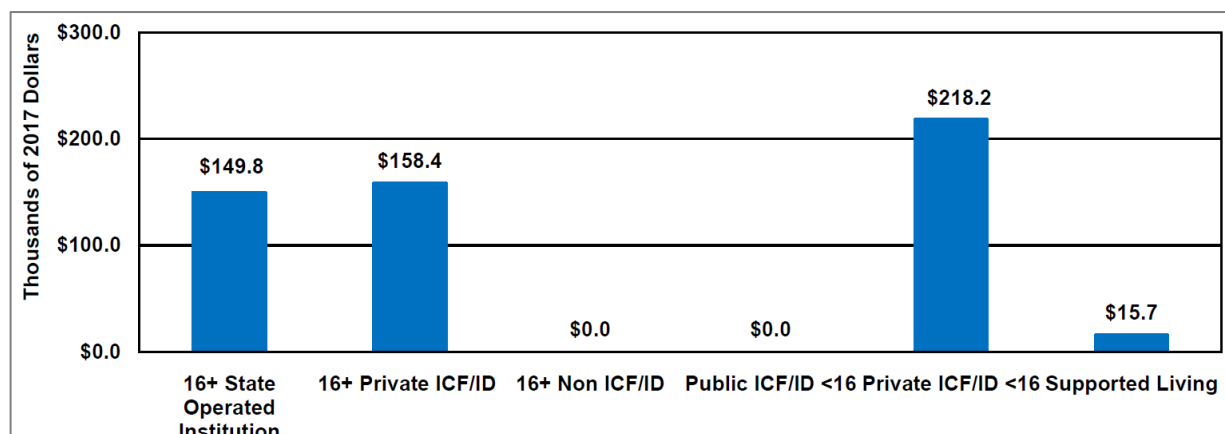
seen in the preceding figures. According to Tanis et al in *The State of the States in Intellectual and Developmental Disabilities* (Tanis, E.S., Lulinski, A., Wu, A., Braddock, D., and Hemp, R., 2021), in 2017 in Florida more than 30,000 persons with I/DD resided in nursing facilities, state institutions, private ICF/IDs, other residential facilities and supported living facilities. The table that follows details counts of persons with I/DD served by facility type and year from 2007 through 2017 for Florida. The corresponding costs by residential setting are shown in the next figure.

TABLE 25. NUMBER OF PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SERVED BY SETTING, FLORIDA, 2007-2017

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
Total	20,905	21,273	21,397	21,885	20,718	21,178	21,131	27,893	28,841	29,873	30,631
16+ Persons	3,815	3,703	3,595	3,576	3,539	3,448	3,302	3,353	3,286	3,386	3,288
Nursing Facilities	1,176	1,140	1,071	1,124	1,120	1,037	919	951	980	1,090	1,005
State Institutions	1,125	1,041	982	902	874	866	852	850	774	774	774
Private ICF/IID	1,273	1,279	1,287	1,288	1,275	1,286	1,272	1,298	1,302	1,303	1,321
Other Residential	241	243	255	262	270	259	259	254	230	219	188
7-15 Persons	2,221	2,153	2,177	2,104	2,054	2,091	2,087	2,091	2,118	2,107	2,129
Public ICF/IID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/IID	531	527	521	518	498	484	470	417	422	397	396
Other Residential	1,690	1,626	1,596	1,586	1,556	1,607	1,617	1,674	1,696	1,710	1,733
≤6 Persons	14,869	15,417	15,685	16,205	15,125	15,639	15,742	22,449	23,437	24,380	25,214
Public ICF/IID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/IID	192	194	194	201	203	204	199	219	211	215	216
Supported Living	8,824	9,059	9,106	9,478	8,286	8,623	8,799	15,307	16,001	16,762	17,292

Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 34. ANNUAL COST OF CARE BY RESIDENTIAL SETTING, FLORIDA, FISCAL YEAR 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

The Florida APD operates two state-run ICF/IIDs that together house and serve more than 700 residents. Tacachale Center in Gainesville is home to about 200 persons with I/DD while the Sunland Centers in Marianna served more than 500 individuals. Both centers strive to ensure all residents receive quality care and treatments along with training to support and strengthen self-determination. Community involvement and community living are fostered along with individualized goal setting towards self-determination and independence (Florida Agency for Persons with Disabilities, n.d.).

In summary, Florida's population growth, an aging population of both persons with I/DD and their caregivers, rising health and related service costs, workforce challenges, and competing funding priorities contribute to escalating concerns about the adequacy and sustainability of the health care and other services and supports for persons with I/DD in facilities. Increases in total funding, as seen in recent years, are insufficient to close existing gaps while accommodating rising numbers of persons with I/DD in need of the specialized care they deserve that is provided in these facilities.

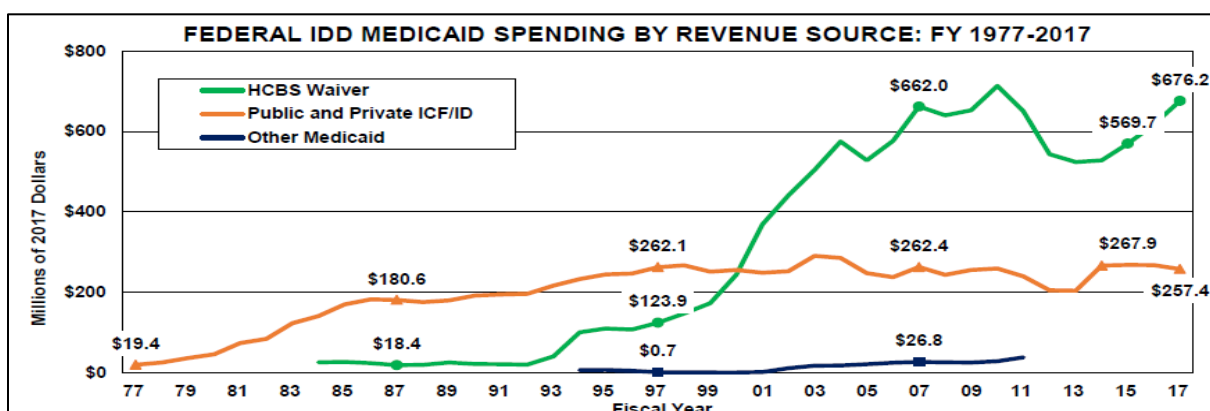
Note: Add information from Social Security Act document

ANALYSIS OF ADEQUACY OF HOME AND COMMUNITY-BASED WAIVER SERVICES (HCBS)

In Florida, federal Medicaid intellectual and developmental disability service spending for the HCBS Waiver took a precipitous turn upward around the year 2000, while spending by public and private revenue sources were nearly level with a slight downturn in 2017. The figure below shows that in fiscal year 2017 in Florida, of the 1.53 billion dollars spent by federal and state Medicaid on intellectual and

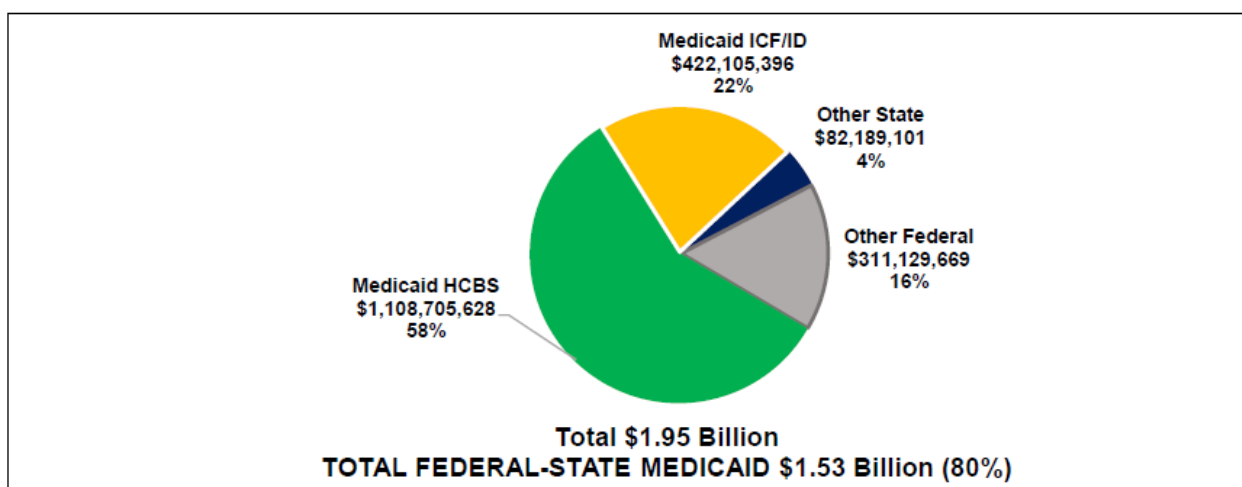
developmental disability services, about 58 percent was in the Medicaid HCBS category, and 22 percent in Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities, followed by 16 percent in other federal spending and four (4) percent in other state Medicaid spending. HCBS Waiver costs by fiscal year per participant in Florida were most recently reported at \$32,700.

FIGURE 35. FEDERAL INTELLECTUAL AND DEVELOPMENTAL DISABILITY MEDICAID SPENDING BY REVENUE SOURCE, FLORIDA, FISCAL YEAR 1977-2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

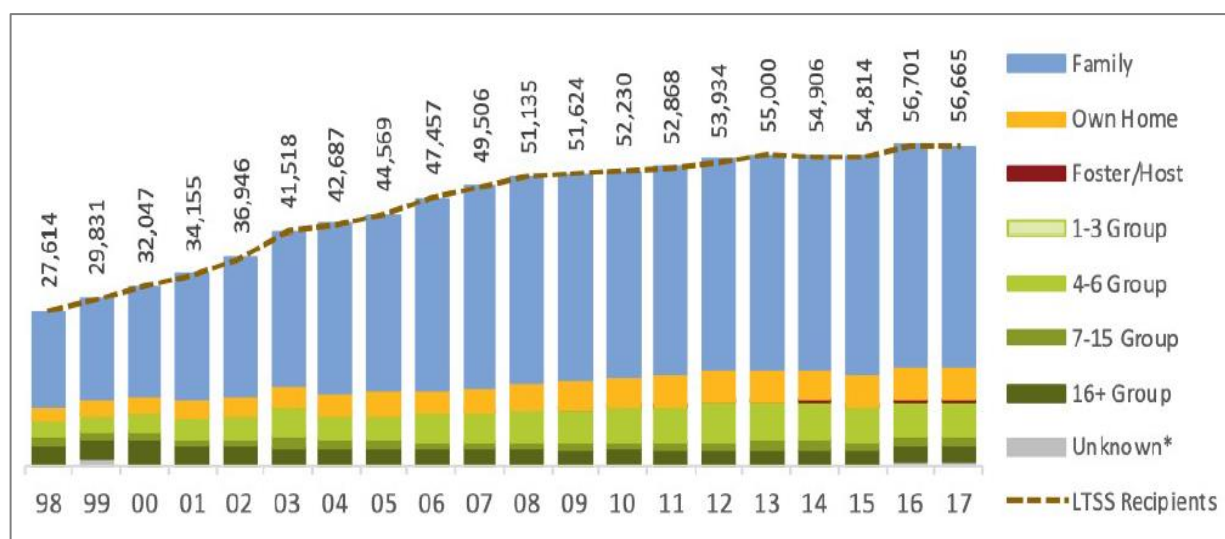
FIGURE 36. FEDERAL-STATE MEDICAID AS A PERCENTAGE OF TOTAL INTELLECTUAL AND DEVELOPMENTAL DISABILITY SPENDING, FLORIDA, FISCAL YEAR 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

As described earlier, data from the National Residential Information Systems Project (RISP) indicated that since 2005 through 2016, the vast majority of persons with I/DD who lived in individualized settings, resided in a family home. As Florida's population grows the prevalence of I/DD will increase, placing increasing demand on home and community-based supports and services. Florida's numbers of individuals who live in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) remained relatively constant from 1982 to 2017, as seen in the RISP data below. The waitlist for iBudget Florida waivers hovers above 20,000 individuals, while the Agency for Persons with Disabilities (APD) caseload, including persons living in the home of a family while on the waitlist, increased incrementally to more than 58,000 persons (University of Minnesota, Residential Information Systems Project (RISP), Research and Training Center on Community Living, Institute on Community Integration, 2017).

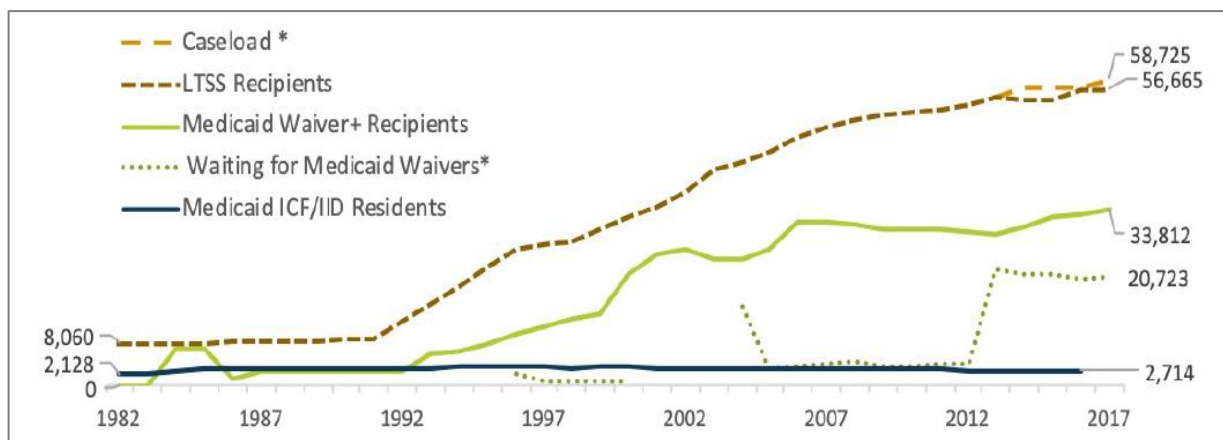
FIGURE 37. FLORIDA LONG-TERM SERVICES AND SUPPORTS FOR PERSONS WITH I/DD BY RESIDENCE TYPE, FLORIDA, 1998 - 2017



Source: University of Minnesota, Residential Information Systems Project (RISP), Research and Training Center on Community Living, Institute on Community Integration, 2017

As noted in a previous section, Florida Agency for Persons with Disabilities (APD) had a waiting list of 22,865 persons in February 2020. Florida has the highest percentage of persons on a waiting list living with aging caregivers in the United States. An individual over the age of 60 who is caring for their adult child is deemed an aging caregiver. The figure below displays the trends in numbers of long-term support and services recipients; Medicaid recipients; and those on the waiting list.

FIGURE 38. FLORIDA LONG-TERM SUPPORTS AND SERVICES, MEDICAID RECIPIENTS, AND THOSE ON THE WAITLIST, FLORIDA, 1998 - 2017

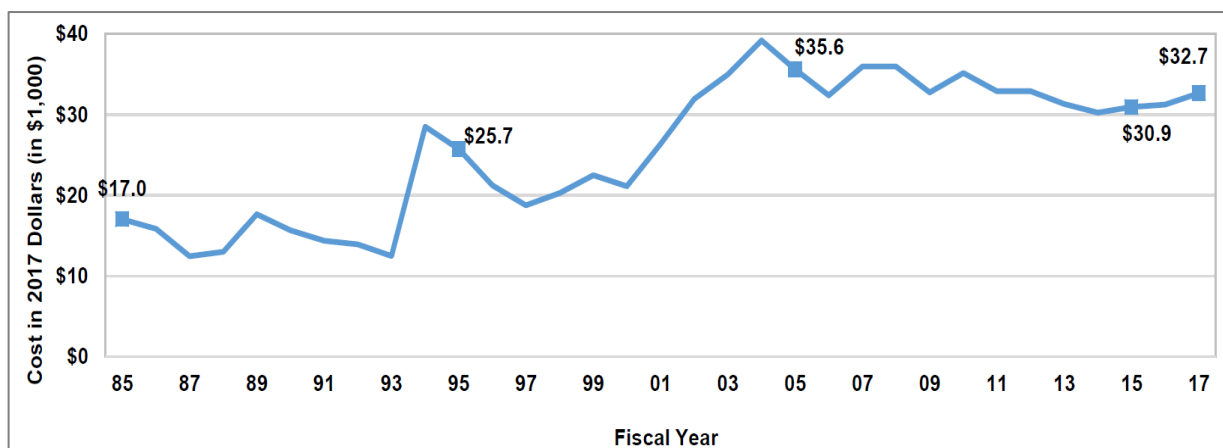


*APD caseload, waiting while living in the home of a family member

Source: University of Minnesota, Residential Information Systems Project (RISP), Research and Training Center on Community Living, Institute on Community Integration, 2017

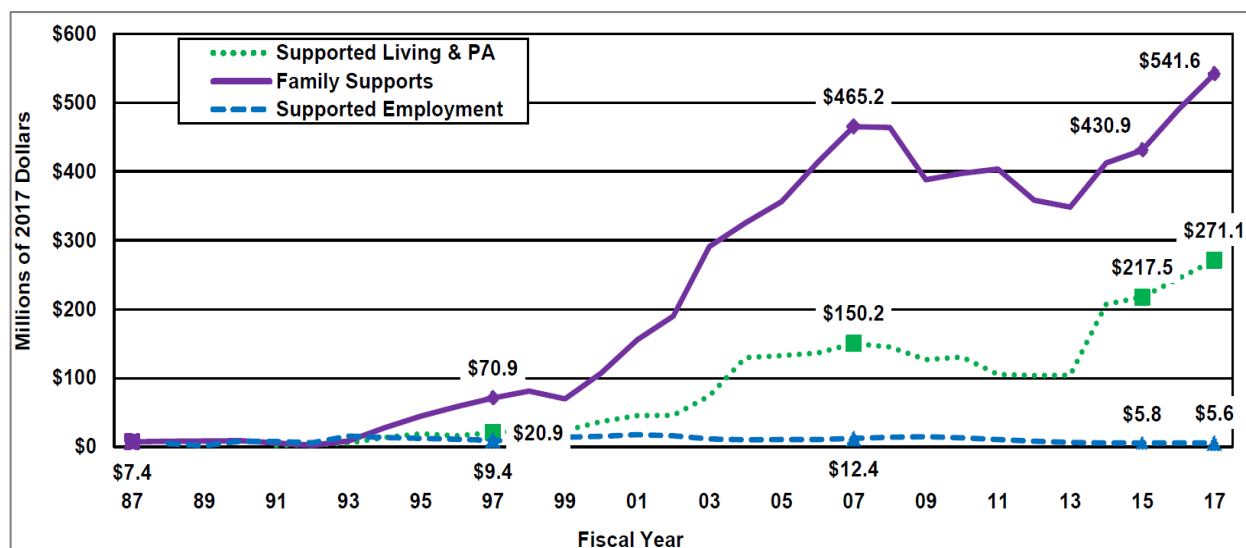
Costs and spending for HCBS are shown in the next series of figures. Per participant costs are incrementally rising while spending for family supports and supported living and personal assistance have taken much sharper upward turns. Supported employment spending remained almost level.

FIGURE 39. HOME AND COMMUNITY-BASED SERVICES WAIVER COST PER PARTICIPANT, FLORIDA, FISCAL YEARS 1985 - 2017



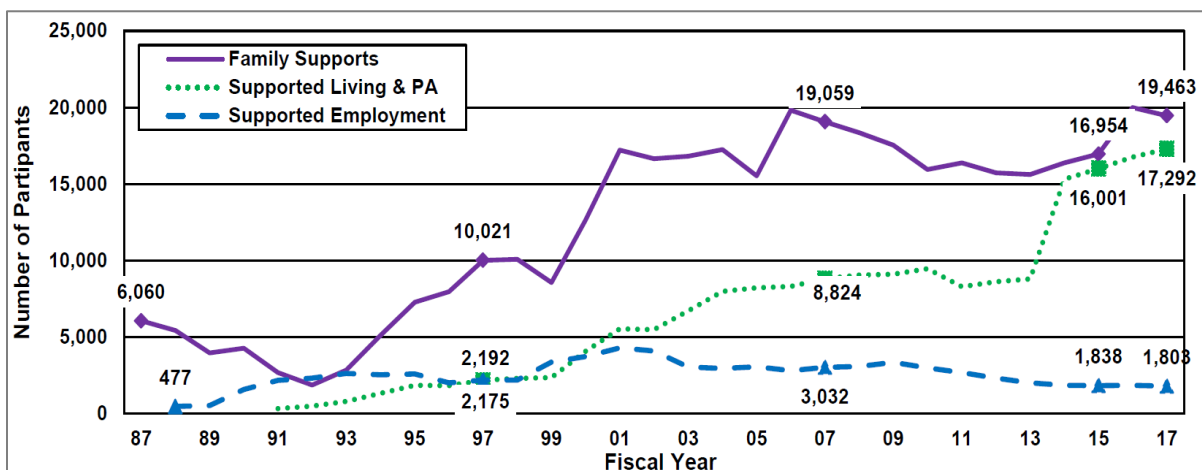
Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 40. INDIVIDUAL AND FAMILY SUPPORT, FLORIDA, FISCAL YEARS 1987 - 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 41. INDIVIDUAL AND FAMILY SUPPORT PARTICIPANTS, FLORIDA, FISCAL YEARS 1987 - 2017

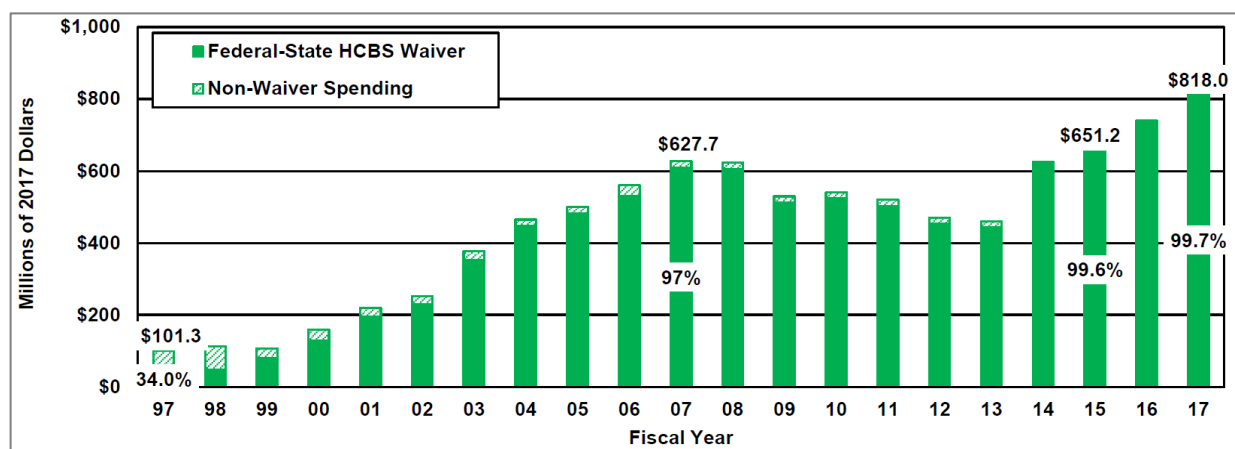


Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

Similar to spending trends, in recent years in Florida the numbers of family support participants have risen notably as has the number of participants using supported living and personal assistance services.

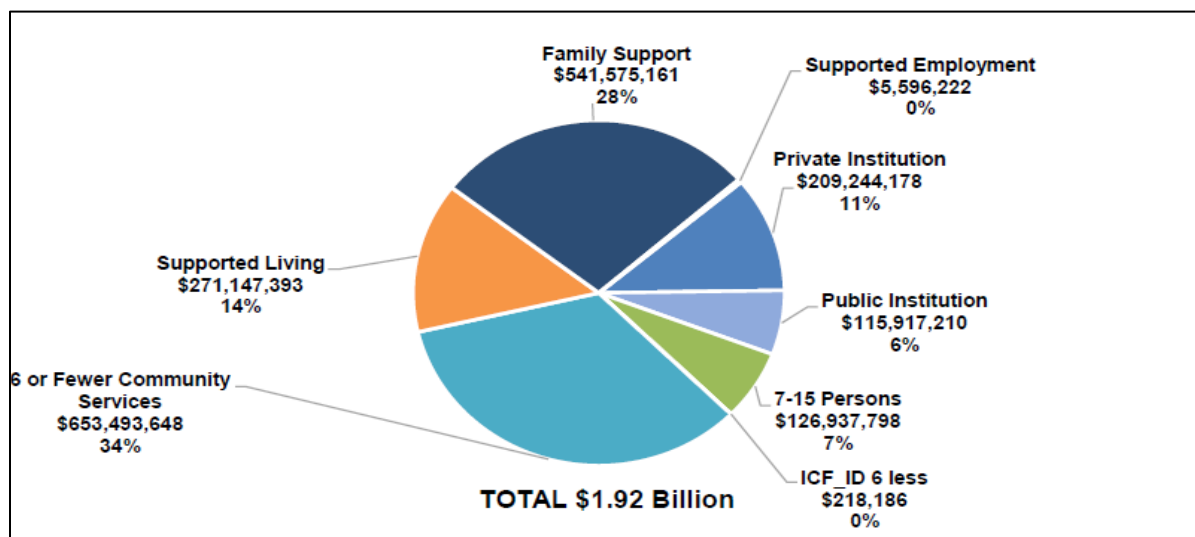
As shown in the figure below, in Florida the revenue source for 99.7 percent of spending is the federal-state HCBS waiver. The percentages of Florida's 2017 total spending of 1.92 billion dollars for individual and family support are shown in a figure below.

FIGURE 42. INDIVIDUAL AND FAMILY SUPPORT SPENDING BY REVENUE SOURCE, FLORIDA, FISCAL YEARS 1997 - 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

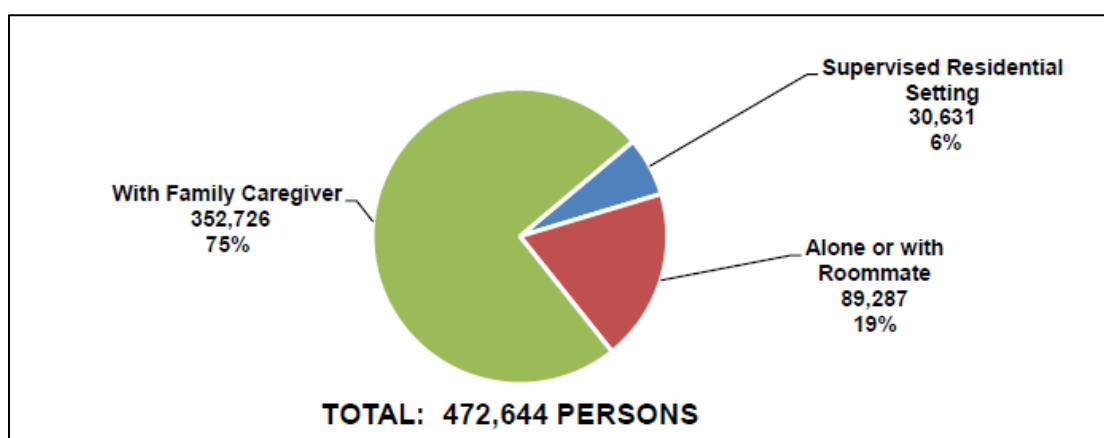
FIGURE 43. INDIVIDUAL AND FAMILY SUPPORT AS A PERCENTAGE OF TOTAL SPENDING, FLORIDA, FISCAL YEAR 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

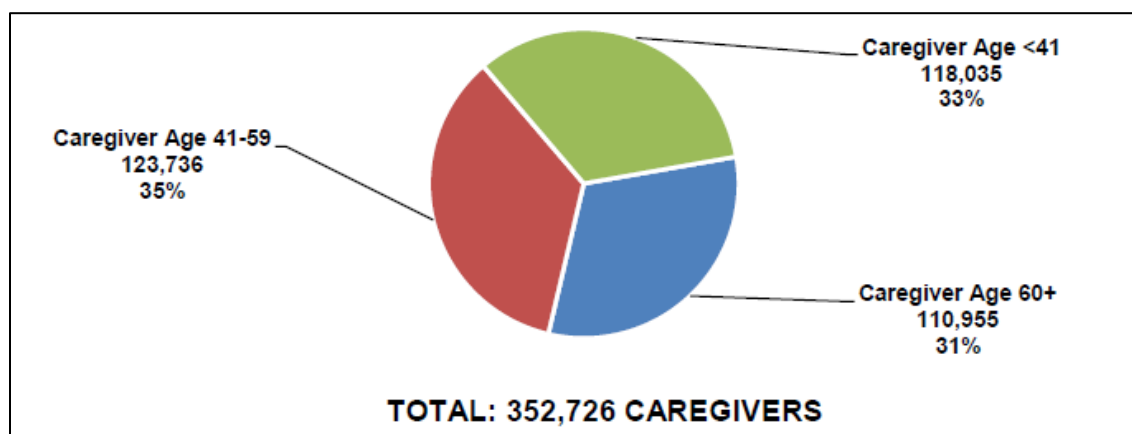
Additional data to underscore the need for investments in HBCS in Florida are shown in the figures that follow. Seventy-five (75) percent of persons with I/DD live with a family caregiver. Only one-third (33 percent) of persons with I/DD live with family caregivers under the age 41 and almost as many (31 percent) live with aging caregivers, that is, a caregiver aged 60 and above. In 2017 in Florida there were more than 350,000 caregiving families with only about six (6) percent receiving support from the state I/DD agency, that is, Florida's APD.

FIGURE 44. ESTIMATED NUMBER OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES BY LIVING ARRANGEMENT, FLORIDA, FISCAL YEAR 2017



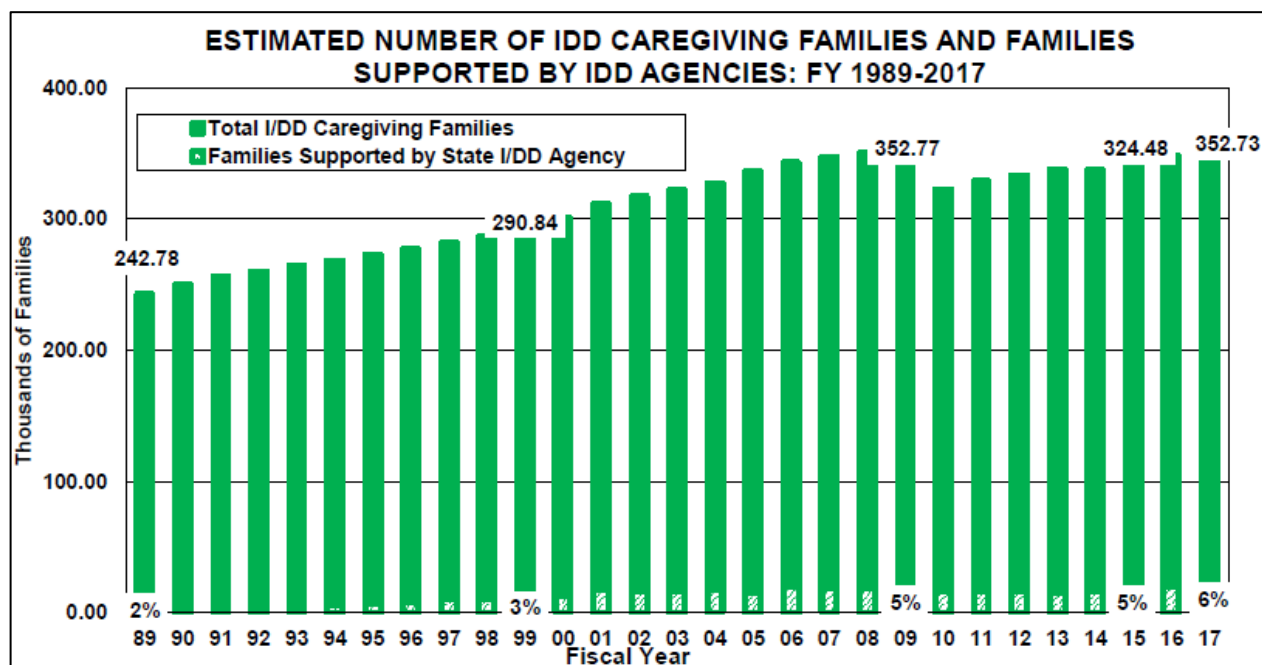
Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 45. ESTIMATED NUMBER OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES BY AGE GROUP LIVING WITH FAMILY CAREGIVERS, FLORIDA, FISCAL YEAR 2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

FIGURE 46. ESTIMATED NUMBER OF INTELLECTUAL AND DEVELOPMENTAL DISABILITY CAREGIVING FAMILIES AND FAMILIES SUPPORTED BY IDD AGENCIES, FLORIDA, FISCAL YEARS 1989-2017



Source: Tanis, State of the States in Intellectual Disabilities, Florida Profile, 2021

Persons with I/DD, their family and caregivers face challenges in many regards, few greater than in the area of Florida's adequacy to deliver quality, timely and sufficient HBCS. Shifting demographics make the issue more complex and more urgent for Florida to address. APD, Florida's state agency responsible for administering HBCS waiver and individual budgeting (iBudget) has led these efforts since 2013. The Florida Legislature continues to focus on the waiver budget and APD with eye towards both efficiency and meeting the health care needs of persons with I/DD in an environment of rising costs, challenging provider reimbursement rates, and workforce capacity and supply. Bold leadership and creative system changes are in order to thwart the further erosion of health, safety, and quality of life for persons with I/DD and those who care for them.

Identification of Strategic Priorities and Goals

PROCESS AND CRITERIA FOR SELECTION

Florida Developmental Disabilities Council Members approached the selection of strategic priorities for the next five years using a methodical, data-driven, and collaborative process. The first step included the sharing, review and discussion of the secondary and primary data from the comprehensive review and analysis. On May 14, 2020, WellFlorida Council presented highlights from the assessment that included state information on developmental disabilities in Florida and a portrait of health care, employment, informal and formal services and supports, interagency initiatives, education and early intervention, quality assurance, housing, transportation, childcare and recreation. Findings and themes from the public input phase of the assessment were shared. These included highlights from a focus group of self-advocate leaders and 16 key informant interviews along with summary findings from the self-advocate survey and caregiver/family member survey. The presentation slides, a recording of the presentation and supporting data compendium were made available to Council Members for their further study and review. Based on these findings, Council Members requested additional in-depth information from two emerging priority groups; that is, self-advocates and aging caregivers of persons with I/DD. Two focus groups were convened in June 2020 as described earlier in this report and the information gained was used to strategize goal, objective and action planning. A week in advance of the August FDDC Council meeting, a virtual “drop in” session was held in which members could ask any remaining questions about the comprehensive review and analysis, secondary or primary data, or findings presented to date.

The FDDC Council Members discussed and approved the criteria proposed by WellFlorida Council. Typical criteria used in strategic planning include:

- Data-informed
- Importance
- Impact
- Urgency
- Feasibility
- Resource availability

TABLE 26: CRITERIA FOR RANKING STRATEGIC PRIORITY ISSUES, FDDC, 2020

Importance and Urgency	Impact	Feasibility	Resource Availability
<ul style="list-style-type: none"> • Issue severity • Burden to large or priority populations • Of great community concern • Focus on equity 	<ul style="list-style-type: none"> • Potential effectiveness • Cross cutting or targeted reach • Ability to demonstrate progress 	<ul style="list-style-type: none"> • Community capacity • Political will • Acceptability to the community 	<ul style="list-style-type: none"> • Financial costs • Staffing • Stakeholder support • Time

Source: Adapted from (National Association of County and City Health Officials, n.d.)

The catalog of initial issues discussed at the May 15, 2020 FDDC Meeting included the following:

- Transportation
- Access to information about available services
- Access to services
- System coordination for continuity of services
- Aging caregivers
- Aging self-advocates
- Dual diagnosis (I/DD and mental health problems)
- Transition to adulthood for self-advocates
- iBudget preservation
- Managed care role in providing community support services
- Critical analysis of agency spending on services and supports
- Emergency preparedness
- Emerging threats

INTERSECTING THEMES

Presented below are the intersecting themes or major needs and issues for persons with I/DD and their families and caregivers. These intersecting themes were also considered in the identification and prioritization of potential strategic issues. For ease of understanding common themes and root causes, the key issues are grouped below into categories including social determinants of health, health status and health behaviors, health resources, and community infrastructure. Many of the key issues emerged as concerns across the intersecting theme areas shown below; however, each issue is only listed once. It is important to note that going forward in their discussions, Council Members opted to use the term dual diagnosis to describe the areas of concern related to severe behavioral issues, maladaptive behaviors, and co-occurring diagnoses of I/DD and mental health issues.

INTERSECTING THEMES, NEEDS, AND ISSUES

- Access to Community Services and Supports
 - Availability and access to services, supports, providers
 - Meeting basic housing and transportation needs
 - Recreational opportunities
 - Social acceptance and supports
- iBudget Preservation
 - Managed care and service delivery systems including Medicaid
 - Wait list
- System Complexity and Accessibility
 - Funding and fiscal accountability of agencies
 - Elimination of mistreatment, bias and discrimination in systems and practices
 - Service quality, uniformity and continuity
- Aging Caregivers and Aging Self-Advocates
 - Caregiver fatigue and burnout
 - Financial burdens for self-advocates and families
 - Rights of self-advocates and caregivers
- Education, Job Training and Employment
 - Post-secondary transition
- Disparity Population
 - Persons with dual diagnosis of I/DD and mental health issue and/or exhibiting maladaptive behaviors or severe behavioral issues

- Emerging Issues
 - Systems change
 - Flexibility to address emergencies and changing conditions

STRATEGIC PRIORITY ISSUE AREAS

At the virtual August 20, 2020 FDDC meeting, the comprehensive review and analysis findings were discussed and organized into the themes presented above. Pandemic conditions required that the prioritization process be conducted virtually. This was accomplished via electronic survey whereby Council Members scored the 26 agreed upon key issues and themes. These were ranked using the criteria shown in the table above. Each key issue was rated for magnitude including importance and urgency and secondly, confidence to successfully address the issue considering its potential impact, feasibility, and resource availability. Council Members also ranked their picks for the top three (3) priority issues. Using a weighted scoring rubric, the ranked list of potential priority issues was generated. At the September 10, 2020 FDDC meeting, survey results were presented and discussed. A facilitated consensus discussion afforded Council Members to ask questions, review data, challenge thinking, advocate for issues, consolidate, remove duplicative topics, and organize themes into issue areas with commonalities such as shared root causes or potential shared strategies for addressing. Council Members refined issue labels to more concisely group them. The priority issue areas below will move forward for consideration in the five year state plan.

STRATEGIC PRIORITY ISSUE AREAS IDENTIFIED

- Access to Services
 - Community support services (services that keep persons with I/DD in the home and community)
 - Meeting basic housing and transportation needs
 - System complexity and support for agencies that provide services including the professionals who provide care and services
 - Service quality, uniformity, continuity and assurance of freedom from bias and discrimination
 - Wait list
- iBudget Preservation
 - Managed care and service delivery systems including Medicaid
 - Fiscal accountability of agencies
- Aging Caregivers

- Aging self-advocates
- Caregiver fatigue and burnout
- Financial planning and financial burden relief for self-advocates, families, and caregivers
- Emerging Issues
 - Systems change
 - Flexibility to address emergencies and changing conditions
- Disparity Population of Persons with Dual Diagnosis of I/DD and Mental Health Issue
 - Resources and services for persons with severe behavioral challenges and/or maladaptive behaviors

Council Members discussed and acknowledged that many of the strategic priority issues have shared root causes, related contributing factors, and will be addressed by common strategies that will have the potential to address multiple issues simultaneously. As part of the assessment process, a number of recommendations and considerations for planning and sustained, successful implementation emerged as a result of discussions among Council Members. As the FDDC moves forward with planning, it is important to bring these points forward. These points are listed below.

KEY CONSIDERATIONS

- Promote a culture of mutual support as a system of many diverse partners and systems
- Foster a unifying community organizing principle and capacity building system around shared outcomes and measures
- Create a core system of metrics to monitor the performance of the system and to inform collective and individual entity investments in serving persons with I/DD and their families and caregivers
- Develop resource availability and educate on the appropriate utilization of services and programs
- Enhance or create programs to more effectively and efficiently manage related chronic health conditions including those found in aging populations
- Enhance or create policy, programs, and environmental change to address accessibility and safety in communities where persons with I/DD live, work, and play
- Create initiatives to increase the availability of therapies and primary, specialty, dental, and mental health professionals and services
- Consider policy, environmental change, interventions, and programs to address root causes that include social determinants of health, and also examine social structures and institutions that contribute to health inequities

DEVELOPMENT OF FDDC FIVE YEAR STATE PLAN (2022-2026)

In order to develop the five year state plan, a small workgroup including Council staff and Council members met to draft the five year state plan over the course of several months. The draft five year state plan was presented to the full Council on January 22nd 2021. The Council voted to approve the draft plan and move forward with the required 45 day public input time period. WellFlorida Council developed and FDDC staff approved a public input survey that was available in four versions: English standard, English Easy Read, Spanish standard, Spanish Easy Read. At the conclusion of the 45 day public input time period, 141 completed surveys were analyzed. The proposed five year state plan received strong support from survey respondents. Based on the public input received, the five year state plan was adopted as drafted and no changes were recommended.

FDDC Five Year State Plan (2022-2026)

FDDC New Five Year State Plan – Goals, Objectives, and Key Activities

(COUNCIL APPROVED FOR PUBLIC INPUT 01/22/2021)

(PUBLIC INPUT DID NOT WARRANT CHANGES PER 04/09/2021 DISCUSSION WITH FDDC EXECUTIVE DIRECTOR, VALERIE BREEN, AND STATE PLAN COMMITTEE CHAIR, DR. JEAN SHERMAN)

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) I/DD information and resource delivery system across the lifespan will be established through a collaborative with the Developmental Disabilities (DD) network partners and effectively utilized by a minimum of 150 family members state-wide.

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 an Access to Services through Knowledge (ASK) state-wide research project designed to identify key community resources along the lifespan.

Key Activity 1.1.3: Identify and update or develop an interactive Access to Services through Knowledge (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 Access to Services through Knowledge (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 I/DD.

Priority Area: HOME AND COMMUNITY-BASED DELIVERY SYSTEMS

<p>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.</p>
<p>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.</p>
<p>Key Activity 2.1.1.: Establish and fully implement a best practice, quality case management system for individuals with I/DD.</p> <p>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.</p> <p>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 for individuals with I/DD.</p>
<p>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.</p>
<p>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.</p> <p>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.</p> <p>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 for individuals with I/DD.</p>
<p>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).</p>
<p>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.</p>

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 for individuals with I/DD.

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: 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.

Objective 4.2: 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.

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 five 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.

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Appendix

This Appendix includes the following sections:

- FDDC Council Members and Strategic Planning Contributors
- Focus Group Scripts
- Key Informant Interview Script
- Survey Instruments

FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL MEMBERS

- Amanda Baker, Tallahassee
- Ginnifer Barber, Department of Elder Affairs, Tallahassee
- Richard Bradley, Yankeetown
- Conney Dahn, Stuart
- Allison Flanagan, Division of Vocational Rehabilitation, Tallahassee
- Lise Fox, Ph.D., Florida Center for Inclusive Communities, University of South Florida
- Victoria Gaitanis, Department of Education, Bureau of Exceptional Education and Student Services
- Sarah Goldman, Tallahassee
- Elly Hagen, Fort Myers
- Cherie Hall, Disability Rights Florida
- Eddie Hall, Lakeland
- Laurie J. Harlow, Tampa
- Dennis Hart, MD, Bradenton
- Yolanda Herrera, Hialeah
- Susan Kabot, Ed.D, CCC-SLP, Plantation
- Jack Kosik, Lakeland
- Robert Karch, MD, MPH, FAAP, Florida Department of Health, Division of Children's Medical Services, Tallahassee
- Kevin Johnson, Celebration
- Lisa Miller, Lakeland
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- Barbara Palmer, Agency for Persons with Disabilities, Tallahassee
- Frank Shalett, Lakeland
- Jean Sherman, Ed.D, RN, Mailman Center UCEDD, University of Miami, Pembroke Pines
- Erica Floyd Thomas, Agency for Health Care Administration, Tallahassee
- Louis Towson, Marianna
- Kali Wilson, Palm Harbor
- Victoria Vangalis Zepp, Tampa

FOCUS GROUP SCRIPTS

Florida Developmental Disabilities Focus Group Protocols Partners in Policymaking

Good _____ and welcome to this focus group. My name is _____ of WellFlorida Council, one of the state's 11 local health planning councils. I have been asked by Florida Developmental Disabilities Council to moderate today's session. The FDDC is responsible for identifying the problems or needs of persons with I/DD and their families in Florida and to do so, the Council creates a plan every 5 years. This focus group will provide information to the FDDC so that they may develop the plan.

We provided you with written information about this focus group process in the Informed Consent form which you have read and signed. Again, we want to make it clear that your participation is voluntary and your identities will be kept confidential.

You have been invited by the Council to participate in this focus group organized to gain insights into the priorities of persons with I/DD and their families in Florida. Through this structured and moderated discussion, we are looking for suggestions and ideas that the Council members can use to begin to formulate strategies and plans for the next 5 years. We will have a diverse group of stakeholders in this focus group and soon we will introduce ourselves.

A focus group is a discussion among people who have something in common. In this case, you are all participant in Partners in Policymaking. So I'd like to thank you for agreeing to join our discussion group on services for persons with I/DD in Florida and their families.

To help manage our discussion, we need to review some guidelines:

- It is important that we hear from everyone and not miss important ideas. So please speak up and only one person should talk at a time.
- We will be on a first name basis but in our final report there will not be any names attached to comments. You may be assured of complete confidentiality. Please respect each other's privacy and agree not to talk about what you hear in this meeting with anyone outside this room.
- We are taping today's meeting. The tape will only be used by our staff to make sure that our written reports are accurate. We do not want to miss any of your comments. These tapes will remain completely confidential.

- If you have a cell phone, please silence it. If you must answer the phone, please do so outside and return as quickly as you can.

Our session will last about one and half hours, and we will not be taking a formal break. If you must use the restroom, they are located _____.

Are there any questions about what we're doing today?

If there are no additional questions, we'll begin. You will notice that we have placed name cards on the table in front of you to help us remember each other's names. Let's find out some more about each other by going around the room one at a time. To get things going, please tell us your name; how long you have lived in Florida; and what is your favorite food, book, movie or television show?

Advocacy and Partners in Policymaking Section: (will not read this subtitle to participants)

1. What does the term "advocacy" or "self-advocacy" mean to you?
 - a. What are you advocating for?
2. What is the biggest personal challenge you have in being an advocate or a self-advocate?
3. How did Partners in Policymaking help you learn to be a better advocate or self-advocate?
4. What else can the Council do to help you effectively advocate or self-advocate once Partners in Policymaking training is over?

Perception on Biggest Issues: (will not read this subtitle to participants)

5. What is the biggest issue for persons with I/DD in Florida?
6. What is the biggest issue for family members or caregivers?
7. What do you think about the services for self-advocates and their families in Florida?

Special Populations: (will not read this subtitle to participants)

8. Are there persons with I/DD in Florida, or groups of persons with I/DD (e.g., non-English speaking people) who do not get the services they need? Who are they?

- a. What are the barriers unique to them?
9. Does race, ethnicity or sexual orientation of persons with I/DD in Florida influence their ability to get the services they need? How?
10. For those of you living in rural areas of Florida, do you experience barriers getting services due to your location? If so, what barriers do you experience and why?

Time Permitting:

11. What are your thoughts and experiences regarding specifically the Medicaid waiver and the process of applying for and qualifying for it?

Florida Developmental Disabilities Focus Group Protocols Self-Advocates

Good morning and welcome to this focus group. My name is _____ of WellFlorida Council, one of the state's 11 local health planning councils. I have been asked by Florida Developmental Disabilities Council to moderate today's session. The FDDC is responsible for identifying the problems or needs of persons with developmental disabilities and their families in Florida and to do so, the Council creates a plan every 5 years. This focus group will provide information to the FDDC so that they may develop the plan.

You have been invited by the Council to participate in this focus group organized to gain insights into the priorities of individuals with intellectual and developmental disabilities. Through this structured and moderated discussion, we are looking for suggestions and ideas that the Council members can use to begin to formulate strategies and plans for the next 5 years. We will have a diverse group of stakeholders in this focus group and soon we will introduce ourselves.

A focus group is a discussion among people who have something in common. So I'd like to thank you for agreeing to join our discussion group on services for self-advocates with I/DD. We also would like to take the time to thank you all for being so flexible with Zoom and apologize for any difficulty that you may have had.

To help manage our discussion, we need to review some guidelines:

- It is important that we hear from everyone and not miss important ideas. So please remain muted on Zoom, as only one person should talk at a time. As a reminder, if you are calling in, you may Mute and Unmute yourself by pressing *6. Others who are using Zoom can use the Mute and Unmute button to do so.
- We will be on a first name basis but in our final report there will not be any names attached to comments. You may be assured of complete confidentiality. Please respect each other's privacy and agree not to talk about what you hear in this meeting with anyone outside this room.
- We are recording today's meeting via Zoom. The tape will only be used by our staff to make sure that our written reports are accurate. We do not want to miss any of your comments. This recording will remain completely confidential.
- If you are using a computer/ tablet to join, please ensure to silence your cell phone. If you are calling in on your phone and have an incoming call that you must answer, you are free to leave the call and dial back in when finished.

Our session will last about one and half hours, and we will not be taking a formal break. If you should need to use the restroom or have anything that you may need to tend to during this time, please feel free to do so. Are there any questions about what we're doing today?

If there are no additional questions, we'll begin. Let's start this off by finding out some more about each other. This will be a perfect time to practice muting and unmuting ourselves to answer. To get things going, please tell us your name; how long you have lived in Florida; and what is your favorite flavor of ice cream?

Now that we have all familiarized ourselves, let's begin.

1. What are the most important issues you believe self-advocates living with an intellectual or developmental disability are facing today?
2. What is the biggest issue YOU are facing today?
3. What kind of help do you currently have from others, and who are they?
4. If you have a caregiver who helps you with physical or financial needs, what would happen to you if that caregiver was no longer able to help you?
5. What changes to the level of support you receive would impact your ability to live independently?
6. What was your experience with the Florida I/DD system when you transitioned from childhood to adulthood? Were you able to find and get the services you needed? If not, what services did you need that you didn't get?
7. If you could design a service system for people living with your type of disability, what would it look like? What new services would be included? What current services would be included? Which service providers or professionals would be needed?
8. What has your experience been with the Medicaid waiver? What has been your experience like when you try to change or add services?
9. If the Florida Developmental Disabilities Council (FDDC) had to pick one thing to change, what would it be?

Thank you for joining us today. Again, all comments will be kept confidential and no names will be shared. We greatly appreciate your input and are looking forward to utilizing your comments in directing the Council's 5 year state plan.

Florida Developmental Disabilities Focus Group Protocols

Aging Caregivers

Good Afternoon and welcome to this focus group. My name is Lindsey Redding of WellFlorida Council, one of the state's 11 local health planning councils. I have been asked by Florida Developmental Disabilities Council to moderate today's session. The FDDC is responsible for identifying the problems or needs of persons with developmental disabilities and their families in Florida and to do so, the Council creates a plan every 5 years. This focus group will provide information to the FDDC so that they may develop the plan.

You have been invited by the Council to participate in this focus group organized to gain insights into the priorities of aging caregivers and their family members with intellectual and developmental disabilities. Through this structured and moderated discussion, we are looking for suggestions and ideas that the Council members can use to begin to formulate strategies and plans for the next 5 years. We will have a diverse group of stakeholders in this focus group and soon we will introduce ourselves.

A focus group is a discussion among people who have something in common. So I'd like to thank you for agreeing to join our discussion group on services for aging caregivers in Florida and their family members with I/DD. We also would like to take the time to thank you all for being so flexible with Zoom and apologize for any difficulty that you may have had.

To help manage our discussion, we need to review some guidelines:

- It is important that we hear from everyone and not miss important ideas. So please remain muted on Zoom, as only one person should talk at a time. As a reminder, if you are calling in, you may Mute and Unmute yourself by pressing *6. Others who are using Zoom can use the Mute and Unmute button to do so.
- We will be on a first name basis but in our final report there will not be any names attached to comments. You may be assured of complete confidentiality. Please respect each other's privacy and agree not to talk about what you hear in this meeting with anyone outside this room.
- We are recording today's meeting via Zoom. The tape will only be used by our staff to make sure that our written reports are accurate. We do not want to miss any of your comments. This recording will remain completely confidential.
- If you are using a computer/ tablet to join, please ensure to silence your cell phone. If you are calling in on your phone and have an incoming call that you must answer, you are free to leave the call and dial back in when finished.

Our session will last about one and half hours, and we will not be taking a formal break. If you should need to use the restroom or have anything that you may need to tend to during this time, please feel free to do so. Are there any questions about what we're doing today?

If there are no additional questions, we'll begin. Let's start this off by finding out some more about each other. This will be a perfect time to practice muting and unmuting ourselves to answer. To get things going, please tell us your name; how long you have lived in Florida; and what is your favorite flavor of ice cream?

Now that we have all familiarized ourselves, let's begin.

12. What are the most important issues facing older caregivers of aging adults with I/DD today?
13. What are the most significant worries you and your family have?
14. What kinds of help do you currently provide to your family member with a disability on a daily basis? What kinds of help do you provide to your family member with a disability on a weekly basis? (Prompt for types of oversight/supervision provided for a family member living outside the home)
15. If you could design a service system for families like your own, what would it look like? What new services would be included? What current services would be included? What service providers or professionals would be needed?
16. Have you thought about what will happen to your loved one when you are no longer able to provide care? Do you have a long-range plan for care of your loved one? For yourself? What advice would you give to other older parents?
17. How would you rate the current service system in Florida? Use a scale of 1 to 5, where 5 is the best and 1 is the worst. What aspects could be improved?
18. What do you think about the Medicaid waiver and the process of applying for and qualifying for it?
19. If the Florida Developmental Disabilities Council could focus on changing only one thing to help older caregivers of individuals with I/DD, what would it be?
20. What is the biggest issue you believe self-advocates are facing today? (Time-permitting)

Thank you for joining us today. Again, all comments will be kept confidential and no names will be shared. We greatly appreciate your input and are looking forward to utilizing your comments in directing the Council's 5 year state plan.

KEY INFORMANT INTERVIEW SCRIPT

Florida Developmental Disabilities Structured Interview (One-on-One) Questions Key Informants (Professionals, Agencies, Organizations and Other Stakeholders)

These questions will be shared in advance so that informants have a chance to think about them and formulate their responses. In some cases, the responses may be submitted back to us in writing. The “interview” would then be an opportunity to reflect on the informant’s responses and perhaps probe a bit deeper.

NAME OF KEY INFORMANT:

AGENCY OF KEY INFORMANT:

DATE OF INTERVIEW:

NAME OF INTERVIEWER:

OTHER NOTES:

1. Please describe your agency and how it interacts or provides services (directly or indirectly) with persons with I/DD in Florida and their families.
2. Please describe the nature of your partnership, collaboration and/or coordination with the Florida Developmental Disabilities Council?
3. What does the term “systems change” mean to you?
4. What systems of support for persons with I/DD and their families need changing? Why?
5. Are there issues that the FDDC should focus on related to systems change for persons with I/DD in Florida and their families? If so, what are they?
6. What issues related to systems change for persons with I/DD in Florida and their families could you partner on with the Florida Developmental Disabilities Council (or in what ways could current partnerships and cooperation be enhanced)?

7. What is the biggest issue you believe that self-advocates or persons with I/DD in Florida are facing today?
8. What is the biggest issue you believe that families and caregivers of persons with I/DD in Florida are facing today?
9. What is your overall sense of the service delivery system in Florida for persons with I/DD and their families in the state of Florida? Why?
10. Are there any populations of persons with I/DD that may be more underserved than others? If so, what are their greatest barriers? Why are these populations, if any, being underserved?
11. How does race, ethnicity or sexual orientation impact persons with I/DD in Florida?
12. How does living in a rural area versus a suburban or urban area impact person with developmental disabilities in Florida?
13. If the Florida Developmental Disabilities Council could focus on only one service area to help persons with I/DD and their families, what should it be?

SURVEY MATERIALS

SELF-ADVOCATE SURVEY

Florida Developmental Disabilities Council:

Self-Advocate Survey

Tell us about needs, services and experiences for persons with I/DD in Florida by completing this survey.

To be eligible to take this survey you must live in Florida, be a self-advocate (person with a developmental disability) and be at least 18 years of age OR be the authorized representative of a person with a developmental disability who lives in Florida and is at least 18 years of age.

If you are the Caregiver/Family Member of a child with a developmental disability please take the Caregiver/Family Member Survey located at <https://wellflorida.org/surveys/>

Please respond to all surveys before April 20, 2020.

Send questions to fddc@fddc.org

Who is completing this survey?

- ☐ I am a self-advocate (person with a developmental disability)
- ☐ The person with the developmental disability authorized me to fill out this survey
- ☐ None of the above

Does the person with a developmental disability live in Florida?

- ☐ Yes
- ☐ No

In what county does the person with a developmental disability currently live?

▼ Alachua County ... I do not know

What is the age of the person with a developmental disability?

- ☐ Less than 18 years old
 - ☐ 18 - 29
 - ☐ 30 - 39
 - ☐ 40 - 49
 - ☐ 50 - 59
 - ☐ 60 - 64
 - ☐ 65 - 69
 - ☐ 70 or older
-

Where does the person with a developmental disability live?

- ☐ Group Home
 - ☐ Family Home
 - ☐ Intermediate Care Facility (ICF/DD)
 - ☐ His/her own apartment/home
 - ☐ Assisted Living or Nursing Home
 - ☐ Homeless
 - ☐ Other _____
-

Which of these best describes the person with a developmental disability?

- ☐ White
 - ☐ African American or Black
 - ☐ Native American or Alaska Native
 - ☐ Asian
 - ☐ Pacific Islander or Native Hawaiian
 - ☐ Two or more races
 - ☐ Some other race
 - ☐ I prefer not to answer
-

Is the person with a developmental disability Hispanic?

- ☐ Yes
 - ☐ No
 - ☐ I prefer not to answer
-

Which of these best describes the person with a developmental disability?

- ☐ Female
- ☐ Male
- ☐ Transgender
- ☐ I prefer not to answer
- ☐ Not listed (please tell us) _____

Does the person with a developmental disability know what services he/she can get?

- ☐ Yes
 - ☐ Kind of
 - ☐ No
-

What services have the person with a developmental disability used in Florida in the past two (2) years? (Select all that apply.)

- ☐ Abuse hotline, adult or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (including physical, occupational, speech, applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in his/her community
- ☐ Transportation services
- ☐ ☒ The person with a developmental disability has not used any of these services

Is it easy to get the services the person with a developmental disability needs?

- ☐ Yes
- ☐ Kind of
- ☐ No

Does the person with a developmental disability receive all the services he/she needs?

- ☐ Yes
- ☐ No



In the past 2 years, in what areas were the needs of the person with the developmental disability not met? (Select all that apply.)

- ☐ Abuse hotline, adult or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (including physical, occupational, speech, applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in his/her community
- ☐ Transportation services
- ☐ Other _____
-



Why was their need for abuse hotline, adult or child protective services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for employment opportunities and job training services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for medical, mental health, dental health care, and wellness support services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for therapies (including physical, occupational, speech and applied behavioral) not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for education and school services including early identification and ongoing supports throughout schooling not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for housing services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for child care services (before school, afterschool programs, summer camps, and early care services) not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for recreational opportunities not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for transportation services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for other services not met? (Select all reasons)

- ☐ Cost
 - ☐ Waiting list
 - ☐ Accessibility
 - ☐ Transportation
 - ☐ No providers in the area
 - ☐ Eligible for service but no appointments available
 - ☐ Location of service
 - ☐ Service times (cannot go when service times are offered)
 - ☐ Was not eligible for the service
 - ☐ Other (please tell us) _____
-

In the past 2 years, in which of these areas did the person with a developmental disability have the most needs that were not met? (Select one.)

- ☐ Abuse hotline, adult, or child protective services
- ☐ Employment opportunities and supports
- ☐ Medical, mental health, dental care and wellness supports and services
- ☐ Therapies (physical, occupational, speech, applied behavioral)
- ☐ Education and school services including early intervention and continuing school support
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in his/her community
- ☐ Transportation services
- ☐ The person with a developmental disability's needs were met in these areas.



What caused their need for \${Q36/ChoiceGroup/SelectedChoices} to not be met? (Select all that apply)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ No housing in the area
- ☐ No recreation opportunities in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



What services will the person with a developmental disability need in the next 12 months? (Select all that apply.)

- ☐ Abuse hotline, adult, or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (physical, occupational, speech, applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in the community
- ☐ Transportation services
- ☒ No services will be needed

How old are you?

- ☐ Less than 18 years old
 - ☐ 18 - 29
 - ☐ 30 - 39
 - ☐ 40 - 49
 - ☐ 50 - 59
 - ☐ 60 - 64
 - ☐ 65 - 69
 - ☐ 70 or older
-

Do you live in Florida?

- ☐ Yes
 - ☐ No
-

What county do you live in?

▼ Alachua County ... I do not know

Where do you live?

- ☐ Group Home
 - ☐ Family Home
 - ☐ Intermediate Care Facility (ICF/I/DD)
 - ☐ My own apartment/home
 - ☐ Assisted Living or Nursing Home
 - ☐ Homeless
 - ☐ Other _____
-

Which of these best describes you?

- ☐ White
 - ☐ African American or Black
 - ☐ Native American or Alaska Native
 - ☐ Asian
 - ☐ Native Hawaiian or Other Pacific Islander
 - ☐ Two or More Races
 - ☐ Some other Race
 - ☐ I prefer not to answer
-

Are you Hispanic?

- ☐ Yes
 - ☐ No
 - ☐ I prefer not to answer
-

Which of these best describes you?

- ☐ Female
- ☐ Male
- ☐ Transgender
- ☐ I prefer not to answer
- ☐ Not Listed (please tell us) _____

Do you know what services are available to you?

- ☐ Yes
 - ☐ Kind of
 - ☐ No
-



What services have you used in Florida in the past 2 years? (Select all that you have used.)

- ☐ Abuse hotline, adult or child protective services
 - ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
 - ☐ Medical, mental health, dental health care, and wellness support services
 - ☐ Therapies (physical, occupational, speech, applied behavioral)
 - ☐ Education and school services including ongoing supports throughout schooling
 - ☐ Housing services (help finding and keeping safe, affordable living arrangements)
 - ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
 - ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
 - ☐ Recreational opportunities and services in my community
 - ☐ Transportation services
 - ☒ I have not used any services
-

Is it easy to get the services you need?

- ☐ Yes
 - ☐ Kind of
 - ☐ No
-

Do you receive all the services you need?

- ☐ Yes
- ☐ No



In the past 2 years, in what service areas did you have needs that were not met? (Select all the needs that were not met.)

- ☐ Abuse hotline, adult, or child protective services
 - ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
 - ☐ Medical, mental health, dental health care, and wellness support services
 - ☐ Therapies (physical, occupational, speech, applied behavioral)
 - ☐ Education and school services including ongoing supports throughout schooling
 - ☐ Housing services (help finding and keeping safe, affordable living arrangements)
 - ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
 - ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
 - ☐ Recreational opportunities and services in my community
 - ☐ Transportation services
-

What services do you think you will need in the next year (12 months)? (Select all the services you will need.)

- ☐ Abuse hotline, adult, or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (physical, occupational, speech, applied behavioral)
- ☐ Education and school services including ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in my community
- ☐ Transportation services
- ☐ ☒ I will not need any services

CAREGIVER/FAMILY MEMBER SURVEY

Florida Developmental Disabilities Council: Caregiver/Family Member Survey

Tell us about needs, services and experiences for persons with I/DD in Florida by completing this survey.

To be eligible to take this survey you must be 18 years of age or older and the Caregiver or Family Member of a person with a developmental disability who lives in Florida.

If you are a self-advocate (person with a developmental disability) living in Florida and are 18 years of age or older please take the Self-Advocate Survey located at <https://wellflorida.org/surveys/>

Please respond to all surveys before April 20, 2020.

Send questions to fddc@fddc.org

Does the person with the developmental disability live in Florida?

- ☐ Yes
- ☐ No

In what county does the person with the developmental disability currently live?

▼ Alachua County ... I do not know

What is your age?

- ☐ Less than 18 years old
- ☐ 18 - 29
- ☐ 30 - 39
- ☐ 40 - 49
- ☐ 50 - 59
- ☐ 60 - 64
- ☐ 65 - 69
- ☐ 70 or older

Select all categories that best describe your relationship to the person with the developmental disability.

- ☐ Parent
- ☐ Grandparent
- ☐ Brother/Sister
- ☐ Legal Guardian Advocate or Legal Guardian
- ☐ Other _____

Are you the primary caregiver for the person with the developmental disability? (A primary caregiver is responsible for the health, social, emotional and financial well-being of the person with a developmental disability.)

- ☐ Yes
- ☐ No

Do you live in Florida?

- ☐ Yes
- ☐ No

In what county do you live?

▼ Alachua County ... I do not know

Which of these best describes you?

- ☐ White
 - ☐ African American or Black
 - ☐ Native American or Alaska Native
 - ☐ Asian
 - ☐ Pacific Islander or Native Hawaiian
 - ☐ Two or more races
 - ☐ Some other race
 - ☐ I prefer not to answer
-

Are you Hispanic?

- ☐ Yes
 - ☐ No
 - ☐ I prefer not to answer
-

Which of these best describes you?

- ☐ Female
- ☐ Male
- ☐ Transgender
- ☐ I prefer not to answer
- ☐ Not listed (please tell us) _____

The next set of questions will be about the person with the developmental disability.

In what county does the person with a developmental disability currently live?

▼ Alachua County ... I do not know

Where does the person with the developmental disability live?

- ☐ Group Home
 - ☐ Family Home
 - ☐ Intermediate Care Facility (ICF/DD)
 - ☐ His/her own apartment/home
 - ☐ Assisted Living or Nursing Home
 - ☐ Homeless
 - ☐ Other _____
-

What is the age of the person with a developmental disability?

- ☐ Less than 5 years
 - ☐ 5 - 17
 - ☐ 18 - 21
 - ☐ 22 - 29
 - ☐ 30 - 39
 - ☐ 40 - 49
 - ☐ 50 - 59
 - ☐ 60 - 64
 - ☐ 65 - 69
 - ☐ 70 or older
-

Which of these best describes the person with a developmental disability?

- ☐ White
 - ☐ African American or Black
 - ☐ Native American or Alaska Native
 - ☐ Asian
 - ☐ Pacific Islander or Native Hawaiian
 - ☐ Two or more races
 - ☐ Some other race
 - ☐ I prefer not to answer
-

Is the person with a developmental disability Hispanic?

- ☐ Yes
 - ☐ No
 - ☐ I prefer not to answer
-

Which of these best describes the person with the developmental disability?

- ☐ Female
- ☐ Male
- ☐ Transgender
- ☐ I prefer not to answer
- ☐ Not listed (please tell us) _____

What services has the person with a developmental disability used in Florida in the past 2 years?
(Select all that apply.)

- ☐ Abuse hotline, adult, or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (including physical, occupational, speech, and applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in his/her community
- ☐ Transportation services
- ☐ ☒ The person with a developmental disability has not used any of these services



In the past two (2) years in what areas did the person with a developmental disability not have their needs met? (Select all areas that apply.)

- ☐ Abuse hotline, adult, or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (including physical, occupational, speech, and applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in his/her community
- ☐ Transportation services
- ☐ Other _____
- ☐ ☒ The person with a developmental disability did not have unmet needs in the past 2 years



Why was their need for abuse hotline, adult or child protective services not met? (Select all reasons.)

- ☐ Did not know who to call
- ☐ Report not accepted
- ☐ Incident determined unfounded
- ☐ Other (please tell us) _____



Why was their need for employment opportunities and job training services not met? (Select all reasons.)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for medical, mental health, dental health care, and wellness support services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for therapies (including physical, occupational, speech, applied behavioral) services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for education and school services including early identification and ongoing supports throughout schooling not met? (Select all reasons.)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for housing services not met? (Select all reasons.)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No housing service providers in the area
- ☐ No housing in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for community support services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ No community support services in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for child care (before school, afterschool programs, summer camps, and early care) services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no spots available for my child
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for recreational opportunities and services in his/her community not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ No recreation opportunities in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why was their need for transportation services not met? (Select all reasons.)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ No transportation service providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



Why were their needs for other services not met? (Select all reasons)

- ☐ Cost
- ☐ Waiting list
- ☐ Accessibility
- ☐ Transportation
- ☐ No providers in the area
- ☐ Eligible for service but no appointments available
- ☐ Location of service
- ☐ Service times (cannot go when service times are offered)
- ☐ Was not eligible for the service
- ☐ Other (please tell us) _____



What are the most important service areas for the person with a developmental disability in your care?
(Select up to three.)

- ☐ Abuse hotline, adult or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (including physical, occupational, speech, and applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in his/her community
- ☐ Transportation services
- ☐ Other _____



What services do you believe the person with a developmental disability will need in the next year (12 months)? (Select all that apply.)

- ☐ Abuse hotline, adult or child protective services
- ☐ Employment opportunities and job training services (finding and keeping employment with or without supports)
- ☐ Medical, mental health, dental health care, and wellness support services
- ☐ Therapies (including physical, occupational, speech, and applied behavioral)
- ☐ Education and school services including early identification and ongoing supports throughout schooling
- ☐ Housing services (help finding and keeping safe, affordable living arrangements)
- ☐ Community support services (for example, respite care, companion services, getting and using assistive technology, counseling services, personal care assistance, faith-based and help with expenses)
- ☐ Child care services (before school, afterschool programs, summer camps, and early care services)
- ☐ Recreational opportunities and services in the community
- ☐ Transportation services
- ☐ No services will be needed



What are the top services or resources you need as a caregiver to be able to best assist the person with the developmental disability? (Select up to three.)

- ☐ Support for an aging caregiver
- ☐ Meeting other families of persons with I/DD
- ☐ Before and after school care, summer camp
- ☐ Respite care
- ☐ Assistance with daily caregiving tasks
- ☐ Local community-based services
- ☐ Assistance with meeting the healthcare needs of persons with I/DD
- ☐ Estate planning
- ☐ Early intervention services
- ☐ Advocacy and leadership training and opportunities
- ☐ Safe and secure housing
- ☐ Getting or using transportation services
- ☐ Assistance with school to adult life transitioning
- ☐ Qualified providers
- ☐ I do not need any resources
- ☐ Other (please tell us) _____



What information do you need as a caregiver to be able to best assist the person with the developmental disability? (Select up to three most important information needs)

- ☐ Information on guardianship options and alternatives
- ☐ Information on caregiver rights and responsibilities
- ☐ Information on how to get services
- ☐ Finding support for an aging caregiver
- ☐ Information on school services
- ☐ Information on benefits and social security eligibility including Medicaid Waiver programs
- ☐ Information on transportation services
- ☐ Information about school to adult life transitioning
- ☐ I do not need any information
- ☐ Other (please tell us) _____



What are the critical issues you face as the primary caregiver of a person with development disabilities? (Select up to three issues)

- ☐ Fatigue, stress and/or burnout
- ☐ Financial issues
- ☐ Personal safety
- ☐ Social isolation
- ☐ Worry about the future
- ☐ Physical health problems (for example, heart disease, back pain, headaches)
- ☐ Mental health-related problems (for example, depression, alcohol or substance misuse)
- ☐ Employment-related issues
- ☐ Managing other family responsibilities
- ☐ Lack of time to pursue own interests
- ☐ Interpersonal relationship/intimate relationship issues
- ☐ Other (please tell us) _____