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PART C. Analysis of State Issues and Challenges

I. Criteria for eligibility for services:

The eligibility criteria, taken from the Agency for Health Care Administration's website (Florida Agency for Health Care Administration, 2021), is described below for Florida's iBudget Home- and Community-Based Services (HCBS) Waiver services and supports and the Consumer Directed Care Plus (CDC+) Waiver.

To be eligible for Florida's iBudget (HCBS) Waiver services and supports, individuals must meet the eligibility requirements in accordance with Chapter 393, F.S.; meet the Level of Care criteria for placement in an Intermediate Care Facility for individuals with Intellectual Disabilities (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.

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; and how they will be provided.

Eligibility criteria for persons who wish to utilize the CDC+ program are as follows: Be a current consumer under the Medicaid Waiver program; live in a family home or own their own home; elect a representative, if needed; complete CDC+ trainings; select a Waiver Support Coordinator trained to provide CDC+ consultant services; pass readiness review test with a score of 85% or better.

Criteria for serving individuals on the HCBS Waiver waiting list include assessment of the severity of the disability or of the situation. The iBudget HCBS Waiver utilizes priority categories

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starting with 1) crisis cases, 2) foster children to be adopted, 3) intensive needs, 4) aging caregiver, 5) transitioning out of school, 6) over 21, and 7) children under 21.

To be eligible for the Statewide Medicaid Managed Care Long-Term Care program (SMMC LTC) program, administered through the Agency for Health Care Administration, individuals must meet the following requirements: Age 65 and over and eligible for Medicaid; or Age 18 and over and eligible for Medicaid due to a disability; and Determined by the Comprehensive Assessment and Review for Long-Term Care Services (CARES) Program at the Department of Elder Affairs (DOEA) to be at nursing home level of care or hospital level of care for persons with cystic fibrosis. The DOEA determines medical eligibility for Medicaid, and the Department of Children and Families (DCF) determines financial eligibility for Medicaid.

Eligibility for the Part C Early Intervention Program in Florida requires a 1.5 standard deviation in two or more developmental domains or 2.0 standard deviations below the mean in one or more domain as measured by appropriate diagnostic instruments and procedures and informed clinical opinion. Historically, Florida's eligibility criterion has been the most restrictive of definitions when compared with other states.

Each school district is responsible for providing services to students who are determined eligible for the following exceptional student education programs: Autism Spectrum Disorder (ASD); Deaf or Hard-of-Hearing (DHH); Ages Birth-5 Years (Birth Through Two Years – Established Conditions or Developmentally Delayed; Ages Three through Five Years – Developmentally Delayed); Dual-Sensory Impairment DSI, Deaf-Blind; Emotional/Behavioral Disability (E/BD); Gifted; Homebound or Hospitalized (HH); Intellectual Disability (InD); Language Impairment (LI); Other Health Impairment (OHI); Orthopedic Impairment (OI); Specific Learning Disability (SLD); Speech Impairment (SI); Traumatic Brain Injury (TBI); and Visual Impairment (VI), Blind and Partially Sighted. Definitions and guidelines for determining eligibility are found in Florida's State Board of Education Rules, Chapter: 6A-6.

For Vocational Rehabilitation services, an Order of Selection is utilized and individuals with the most significant disabilities are served first.

Florida's Working People with Disabilities program for adults who receive services under Florida's Medicaid 1915(c) Waiver programs was approved by the Centers for Medicare and Medicaid Services (CMS) via an amendment for implementation beginning July 2020. Working People with Disabilities allows individuals enrolled in HCBS Waiver programs to still qualify for the waiver even if their income and assets increase due to work. Approved provisions allow for an increase in the monthly income limit up to 550% of the Federal Benefit Rate for individuals with earned income through paid employment, with cash assets up to the amount of \$13,000 for a single individual and \$24,000 for a couple, and the ability for participants to have a retirement account recognized by the Internal Revenue Service. This provision was a direct

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outcome of the Florida Developmental Disabilities Council's efforts to explore how to address income limits identified via eligibility criteria concerns identified in the previous state plan.

Local communities determine their preferences for the category of applicants to receive Housing and Urban Development (HUD) Section 8 housing vouchers from their waiting lists. These preferences can include homelessness, substandard housing, or paying more than 50% of income for rent.

Access to services can be overwhelming for families who have immediate needs and must work through the cumbersome application and eligibility requirements to gain approval for services. Some families and individuals with I/DD simply give up; others turn to peers, advocates, or state and local agencies and organizations with the wherewithal to serve as an advocate and/or assist them with negotiating the process. With waitlists for services and supports, coupled with limitations upon the full range of services and supports available within allowable funding sources, and particularly HCBS Waiver services and supports, Florida desperately needs alternatives to state-funded services and supports.

II. Analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families:

Multiple approaches were used to identify unserved and underserved populations in Florida. 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-advocate members of the state self-advocacy organization, and aging caregivers of persons with I/DD. Surveys were available in Spanish and promoted and distributed statewide to Spanish-speaking groups. Additionally, Easy Read versions of the surveys were developed and issued statewide. All 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.

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 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.

These primary and secondary data results were shared and reviewed with the FDDC 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,

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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, individuals 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).

Secondary data show that more than 20% of Florida's population is 65 years of age or older (United States Census Bureau. *American Community Survey 1-Year Survey*, Table DP05, 2016-2018). In the super senior age group (those 80 years and older), since 1970 Florida's population has seen increases of 77.6% in the 80 to 84 years of age group. The 80 to 84 years of age group represented 2.5% of Florida's total population in 2018 and an increase of more than 300.0% in the 85 years and older age group to reach the 2018 proportion of the population at 2.6% (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% each year (Zablotsky et al., 2017) and 1994/1995 NHIS-D (Larson et al., 2001); United States Census Bureau, *American Community Survey 1-Year Survey*, Table DP05, 2016-2018). 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% of those living with family caregivers have aging caregivers aged 60 years and older (Perkins, 2019). Public input data clearly pointed to aging caregivers as a population of concern. Focus groups also articulated concerns for aging self-advocates as well as the family members who care for them. Almost 50.0% 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% 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% said they need respite care. About one-quarter need resources to meet the health care needs of the person in their care, local community-based services, and daily caregiving task assistance. Nearly 20.0% cited aging caregiver support as a top need (FDDC Caregiver/Family Survey, 2020).

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%) compared to Florida's urban counties (13.1%) (United States Census Bureau. *American Community Survey 5-Year Survey*, Table B17001, 2014-2018). Florida's rural population is older, with 21.3% of the population at 65 years of age or older compared to 19.6% in urban areas (United States Census Bureau. *American Community Survey 5-Year Survey*, Table B01001, 2014-2018). 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

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ranked with all Florida counties. None of Florida's rural counties ranked among the top 10 in the annual rankings (University of Wisconsin Population Health Institute 2020, *2020 County Health Rankings Report*, <http://www.countyhealthrankings.org>). 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.

According to the Agency for Persons with Disabilities, rates of Baker Acts, Florida's law for involuntary crisis commitment 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 involuntary committed for observation. Even though persons with I/DD with Behavior Scores of 5 and 6 only represent 33% of APD consumers, they represent 80.55% of Baker Acts (Agency for Persons with Disabilities (n.d.), APD Report, 2015-20). 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 APD 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 (APD (n.d.), APD Report, 2015-20).

Concerns for persons with I/DD and a dual diagnosis were 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 co-occurring mental illness (i.e., dual diagnosis), may exhibit disruptive behaviors that may be misunderstood by law enforcement leading to restraint and seclusion or placement in restrictive settings. Similarly, data from the Florida Department of Education, Bureau of Exceptional Student Education, reflect higher numbers for restraint and seclusion among students with behavioral issues. 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. This issue reached the level of significance within the past state plan that the Council has already initiated a study in this area.

III. The availability of assistive technology:

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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. FASST is administered through the Florida Department of Education, Division of Vocational Rehabilitation. FAAST's mission focuses on improving the quality of life for all Floridians with disabilities through increasing access to assistive technology services and equipment. 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. FAAST 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. FAAST offers trainings in group settings and focuses on information technology and telecom technology as well as the application of AT in transition, including postsecondary, workplace, and aging. The New Horizon Loan program is a finance program designed to provide assistance to persons with disabilities with purchasing AT with reasonable interest rates; in 2019, the program made 40 such loans. There are six regional demonstration centers (RDCs) 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% 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. FAAST's 1,087 demonstrations reached more than 3,300 individuals, and 13,334 participants benefited from trainings. FAAST trainings were concentrated in Florida's metropolitan areas, where 78.0% of trainings took place (Center for Assistive Technology Act Data Assistance, 2019. *Annual Progress Report Florida 2019*, https://catada.info/apr_reports19/florida_2019).

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% of its client services expenditures on AT (Florida Department of Education, Division of Vocational Rehabilitation, 2019).

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Florida DOE, BESE, assures that students with disabilities have access to assistive technology devices and accompanying services. Services include conducting needs assessments, procuring appropriate assistive technology, designing and adapting equipment, training on equipment use, and maintaining and coordinating 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 DOE, BESE, 2013). Similarly, provisions are in place that allow for certain technology devices to transition with the student upon graduation and exit from public schools.

The Florida Diagnostic and Learning Resources System (FDLRS), a discretionary project of the Florida DOE, BESE, 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 state-wide assistive technology lending library.

Persons with I/DD may have access to AT services through Medicaid and the iBudget Florida HCBS 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.

IV. Waiting Lists:

Year	State Pop (100,000)	Total Served	Number Served per 100,000 state pop.	National Average served per 100,000	Total persons waiting for residential services needed in the next year as reported by the State, per 100,000	Total persons waiting for other services as reported by the State, per 100,000
2017	205.56	33,812	164.5	264.8	100.8	N/A
2016	202.31	32,830	162.3	250.0	101.3	N/A
2015	198.98	32,277	162.2	241.7	107.2	N/A

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- a) Entity who maintains wait-list data in the state for the chart above:
- Case management authorities
 - Providers
 - Counties
 - State Agencies
 - Other _____
- b) There is a statewide standardized data collection system in place for the chart above:
- yes
 - no
- c) Individuals on the waitlist are receiving (select all that apply) for the chart above:
- No services
 - Only case management services
 - Inadequate services
- d) To the extent possible, provide information about how the state places or prioritizes individuals to be on the waitlist:
- Comprehensive services but are waiting for preferred options (e.g., persons in nursing facilities, institutions, or large group homes waiting for HCBS)
 - Other _____

Florida's method for prioritizing individuals on the waitlist for the Developmental Disabilities iBudget HCBS Waiver is based on a system of categories defined in Florida Statute. These categories are as follows: Category 1 includes individuals who are in crisis; Category 2 includes individuals from the child welfare system who are at least 18 but not yet 22 years of age who withdrew their consent to remain in the extended foster care system or who are either transitioning out of the child welfare system due to an adoption or reunification with a family member, permanent placement with a relative, or guardianship with a nonrelative, or are at least 18 but not yet 22 years of age and need both extended foster care and waiver services; Category 3 includes individuals whose caregivers will be unable to provide care, who are at substantial risk of incarceration or court commitment without supports, whose needs place them or their caregiver at risk of serious harm, or who will be discharged from a state mental hospital or skilled nursing home and require a caregiver; Category 4 includes individuals whose caregivers are 70 years of age or older; Category 5 including individuals who are expected to graduate within the next 12 months from secondary school; Category 6 includes individuals who are 21 years of age or older and do not meet one of the other categories; and Category 7 includes individuals who are younger than 21 years of age and do not meet one of the other categories. Individuals who received HCBS Waiver services in another state, who are

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eligible for Florida HCBS Waiver services, and whose parents or legal guardians are active duty military service members who are transferred to Florida, are eligible to receive HCBS Waiver services. As funding is added to move individuals from the waitlist to the HCBS Waiver, if there are not sufficient funds to provide services to all the individuals in a category, a Waitlist Prioritization Tool, which rates the Questionnaire for Situational Information (QSI) assessment, severity risk factors, and family risk factors, has been used.

Funds are available to provide some services to individuals on the HCBS waitlist. These services include, but are not limited to, respite care for children, consumable medical supplies, durable medical equipment, adult day training, transportation, personal supports, dental, residential habilitation, behavioral supports, and in-home subsidies.

As of February 2020, 22,865 individuals were found on the iBudget Waiver waitlist in the following categories: Category 1, Crisis, 0; Category 2, Children in the Welfare System, 0; Category 3, Intensive Needs, 904; Category 4, Caregiver Over Age 70, 230; Category 5, Transition from School, 59; Category 6, Age 21 and Over, 11,455; Category 7, Age Under 21, 10,192; and Priority Not Yet Assessed, 25.

The waitlist for Vocational Rehabilitation, under Order of Selection, uses three categories to prioritize individuals for services. VR's 2019-2020 Annual Report's definition of the three categories and waitlist are described below and reflected only 454 individuals waiting for services in Category 3.

Category 1 – Most Significant Disabilities (0): Limits three or more functional capacities in terms of work; requires three or more primary services; lasts at least 12 months. Category 2 – Significant Disabilities (0): Limits one or two functional capacities in terms of work; requires two or more primary services; lasts at least 6 months. Category 3 – Other Disabilities (454): Does not seriously limit functional capacity in terms of work; lasts less than 6 months.

- e) Description of the state's wait-list definition, including the definitions for other wait lists:

The state's waitlist definition is the same as the state's method for prioritizing individuals on the waitlist. See the response to "d." above for the state's waitlist definition.

- f) Individuals on the waitlist have gone through an eligibility and needs assessment:

yes
 no

Individuals placed on the waitlist have been determined eligible for the Developmental Disabilities iBudget HCBS Waiver services. A needs assessment, referred to as the Questionnaire for Situational Information (QSI) is conducted. This assessment gathers

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information regarding life changes and community inclusion, functional status, behavioral status, and physical status. A short version of a support plan is developed. Annually thereafter, the individuals receive an Annual Status Review, which provides them with an update on their waitlist status and requests information to better understand their current needs.

- g) There are structured activities for individuals or families waiting for services to help them understand their options or assistance in planning their use of supports when they become available (e.g., person-centered planning services):

yes
 no

- h) Specify any other data or information related to wait-lists:

With submission of the 2017-21 Council State Plan, 20,486 individuals with intellectual and developmental disabilities were on the DD waitlist for iBudget HCBS Waiver services. As of February 2020, the waitlist had grown to 22,865 persons waiting for services.

Vocational Rehabilitation continued to reduce its waitlist from 1,275 in Category 3 with submission of the 2017-21 state plan reflecting the May 2016 waitlist, to 454 in Category 3 in 2019-20.

Access to services and supports, with a growing waitlist for iBudget HCBS Waiver services in Florida, continues to be a critical area of concern.

- i) Summary of Waiting List Issues and Challenges

One challenge with the waitlist is that there may never be sufficient HCBS Waiver dollars to fund every individual with intellectual and developmental disabilities and their families in the state who need services and supports, and to adequately fund the services and supports needed by individuals who are removed from the waitlist. The focus on the waitlist, therefore, needs to not only include continued educational and advocacy efforts for the legislature to provide additional funding for HCBS Waiver services, but also strategies for addressing the unmet needs of individuals and their families through other means that may reduce the reliance on the HCBS Waiver.

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% of persons receive services, while 40% are on the waitlist (Agency for Persons with Disabilities, 2020). As of February 2020, the waitlist had 22,865 persons on it, where the total of all individuals waiting for services were separated into categories to assess

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individuals with the highest level of need first. Individuals deemed to be in “crisis” receive priority in accessing services.

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 in Florida must wait until they reach age 70 for their aging, adult children to be prioritized to receive iBudget services.

The iBudget HCBS Waiver waitlist continues to be a significant concern for the Florida Council’s current and future work. Medicaid expansion has been implemented in other states to address the waiting list of services issue. However, Florida has not considered implementation of Medicaid expansion for many factors, even though the Council addressed this issue in our two prior state plans.

V. Analysis of the adequacy of current resources and projected availability of future resources to fund services:

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% from the February rate of 2.3%. 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 3-year 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 3 years to cover services in 10 policy areas. As shown below, general revenue needs in prekindergarten through Grade 12 education, as well as human services, are predicted to increase to 18.5% and 22.9%, 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 for each of

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these 3 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.

Florida's total spending for intellectual and development disability services 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% and 80%, 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% state funded and 65% 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 et al., 2021.)

Special education and related services for school-aged children from 3 to 21 years of age are provided by the Florida Department of Education, Bureau of Exceptional Student Education (BESE) supported by the Individuals with Disabilities Education 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 twelfth grade population, of which 14.0%, or 401,745, were students with disabilities. Students meeting eligibility for services with intellectual disability represent about 7.1% of all students with disabilities, numbering 28,523 in 2019 (Florida Department of Education, Bureau of Exceptional Student Education (BESE), 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% from state sources, about 48.8% from local sources, and 11.3% 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 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). Programs 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

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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, and the Florida Association of Rehabilitation Facilities (Florida 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% of working-age persons with a cognitive disability are employed, compared to 33.3% of those with any disability, and 73.2% 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%, 25.4% for persons with any disability, and highest for persons with a cognitive disability at 28.3%. 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% of closures for persons with I/DD resulting in employment (Winsor, 2019). The percent of supported employment for persons with I/DD is at a low of 12% with the numbers of participants down noticeably (Tanis et al., 2021). This is consistent with the newly released *State Data: The National Report on Employment Services and Outcomes Through 2018*, which indicated that the percentage of individuals with intellectual and developmental disabilities served by APD in integrated employment dropped from 20% in 2011 to 10% in 2018 (Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J., 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

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also in connection with staying in contact with friends and socializing. For example, 47% of NCI survey respondents said lack of transportation was a barrier to seeing friends as compared to 38% nationally. Lack of transportation was the biggest barrier, outscoring money, time, support staff, and rules or regulations. Only 20% of persons with I/DD who responded to the NCI survey reported having attended a self-advocacy meeting or event and about 36% reported having voted in a local or national election (National Core Indicators, 2019).

The legislative allocation of \$10 million in proposed recurring funding to the Transportation Disadvantaged Trust Fund to conduct a broader competitive grant program for Community Transportation Coordinators and Transportation Network Companies, which was initiated in 2019, as well as endeavors by the Florida Council in implementing Transportation Voucher projects, should assist in meeting some future transportation needs.

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 persons with I/DD.

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% 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 systems change and collaboration among federal, state, regional, local and community partners.

VI. Analysis of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive *:

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% 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.

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The Florida APD has continued to operate two developmental disability centers for people who need structured care 24 hours a day (i.e., Tacachale in Gainesville and Sunland in Marianna). Residents at the centers receive medical care, therapy, and may participate in social outings, team sports, community events, vocational training, and onsite work experience. Per the FDDC's 2017-21 State Plan, from FY 2000 to January 1, 2015, there had been a 42.7% decrease in residents living at Sunland and Tacachale, down from 1,483 to 850 individuals. A downward trend has continued with the APD reporting 650 individuals served by the two developmental disability centers in September 2017, and 528 individuals served by both centers in September 2020. (APD Long Range Program Plan. September, 2017.); APD Long Range Program Plan. September, 2020.)).

Review of the 2020 Annual Licensure and Certification reports for Tacachale and Sunland reflected that most of the standards not met centered around Fire/Life/Safety. Most of these pertained to maintenance needs and placement of materials in storage that could present hazards in certain circumstances, and most noted deficiencies were addressed in a timely manner. Concerns emerged, however, for the Sunland Facility I. The number of deficiencies reported at this center were exceptionally high in both November and December 2020, and were not reflected as corrected in AHCA's database as of September 2021. Of particular concern were the report findings related to the presence of mold within at least four housing buildings and the Unit 1 Learning Center. At the time of the findings, "Maintenance staff stated that air scrubbers and dehumidifiers were placed in the housing units to purify the air, but that the mold remediation work had not yet begun." Within the ACHA report, the Superintendent further stated that "No other mitigation work had started except for installing the air scrubbers and dehumidifiers...no additional testing had been performed." The Council initiated follow up on concerns regarding these findings, and AHCA's Deputy Secretary responded, indicating that "The onsite revisit to verify correction of Sunland Facility I's outstanding deficiencies is pending..." Moreover, in August 2021, the U.S. Department of Labor found the Sunland Center, that holds 14(c) certificates authorizing subminimum wage pay for workers with disabilities, was not in compliance with requirements of the Fair Labor Standards Act. As a penalty, the state will be required to pay the full federal minimum wage for every hour the residents worked. An article in the Tallahassee Democrat stated "That means \$304,466 to 163 of those Sunland resident-workers" (Capital Bureau, USA Today Network – Florida, as cited in the Tallahassee Democrat. 2021, August 24). Sunland Center in Marianna to pay more than \$300,000 in back wages (tallahassee.com).

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) deliver rehabilitative and health services to persons with I/DD in protected, residential settings. The need for 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. 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

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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%.

Florida's ICF/IIDs include 38 six (6) bed homes, 27 cluster facilities, six 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 Rehabilitation Facilities, n.d.). In 2020, APD reported serving 1859 individuals in ICF/IIDs (2019-20 OPPAGA Program Summary, Agency for Persons with Disabilities, <https://oppaga.fl.gov>).

In Florida, the number of ICF/IDD beds has remained frozen by a licensure moratorium, though an exception was made with the 2020 legislative session that amends s. 408.036, F.S., to create a certificate of need (CON) exemption for a new ICF/IDD which has a total of 24 beds, comprising three eight-bed homes, for use by individuals exhibiting severe maladaptive behaviors and co-occurring psychiatric diagnoses requiring increased levels of behavioral, medical, and therapeutic oversight. The bill limits the number of CON exemptions authorized to three. The bill includes sunset provisions to repeal the continued licensure requirements and the statutory authority for AHCA to grant the CON exemption created by the bill on July 1, 2022, unless reviewed and saved from repeal by the Legislature. To obtain the exemption, the applicant must not have had a license denied, revoked, or suspended within the 36 months preceding the request for exemption and must have at least 10 years of experience serving individuals with severe maladaptive behaviors in this state. It is unknown how many providers would meet these two criteria and be eligible to apply for a CON exemption under the bill.

The bill also amends s. 400.962, F.S., to establish additional licensure and application requirements for an ICF/IDD with a CON exemption under the bill, including: 1) Each eight-bed home must be co-located on the same property with two other eight-bed homes and must serve individuals with severe maladaptive behaviors and co-occurring psychiatric diagnoses, 2) The total number of beds per home within the facility may not exceed eight, with each resident having his or her own bedroom and bathroom, 3) A minimum of 16 beds within the facility must be designated for individuals with severe maladaptive behaviors who have been assessed using the Matrix with a score of at least Level 4 through Level 6 or assessed using criteria deemed appropriate by the AHCA regarding the need for a specialized placement in an ICFDD, 4) A state-approved staff training curriculum and monitoring requirements specific to the individuals whose behaviors require higher intensity, frequency, and duration of services, 5) Available medical and nursing services 24 hours per day, 7 days per week, 6) Demonstration of a history of

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using interventions that are least restrictive and that follow a behavioral hierarchy, and 7) Maintenance of a policy prohibiting the use of mechanical restraints.

Individuals with developmental disabilities charged with committing a felony crime may be court-ordered into the agency's Developmental Disabilities Defendant Program (DDDP). DDDP is a 146-bed secure facility located in Chattahoochee for defendants with developmental disabilities who are deemed incompetent to participate in their own defense or stand trial. In this program, residents with a secure court order receive competency training and other services in accordance with their needs. This is not a voluntary residential setting. The agency also has 34 secure beds in the Pathways program located at Sunland. In September 2017, the agency reported a daily average population of 120 individuals served. During Fiscal Year 2019-20, the average daily population to whom the DDDP provided services was slightly lower at 106 individuals served (2019-20 OPPAGA Program Summary, Agency for Persons with Disabilities. <https://oppaga.fl.gov>).

In October 2018, the Carlton Palms Educational Center, a for-profit home licensed by APD as the state's largest transitional facility serving 230 individuals with developmental disabilities and behavior disorders, was permanently closed. Residents were moved into group homes ahead of the state mandated schedule to stop operation by March 2019. The Florida Developmental Disabilities Council and Disability Rights Florida, among other state entities with concerns, conducted numerous observational visits prior to its closing. Disability Rights Florida produced a report citing 14 state abuse investigations at the facility in 2015, and 28 more in 2016, which assisted in facilitating closure of the facility (Hudak, S. 2018, October 25, Plagued by abuse claims and deaths, Carlton Palms closes doors to Florida's disabled. *Orlando Sentinel*, <https://www.orlandosentinel.com/news/lake/os-ne-carlton-palms-closes-20181025-story.html>). Within the article, APD staff stated that 21 new group homes were opened all around the state, allowing most residents to move closer to their families.

Similar for both the institutions and private ICF/IIDs is the issue of insufficient effort towards building the capacity of individuals with intellectual and developmental disabilities for self-determination and independence. Individuals with intellectual and developmental disabilities are also residing in nursing homes. In the past, this has been a particularly acute issue for children. Following up on the July 2013 Federal Department of Justice lawsuit against the State of Florida alleging that the state was in violation of the ADA in its administration of its service system for children with significant medical needs, resulting in nearly 200 children with disabilities being unnecessarily segregated in nursing homes when they could be served in their family homes or other community settings, the case appears to have stalled in the courts in 2019. No changes have been reported beyond the Agency for Health Care Administration's announcement that rules for alternative residential options for these children would be developed. In September 2021, seven APD clients under the age of 18 were reflected with a "living setting of nursing home." Previous numbers indicated that nursing homes serving

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children decreased from six to three with 230 children served in nursing homes in July 2012 to 145 children served in nursing homes in July 2016 (FDDC, 2017-2021 State Plan).

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 persons with I/DD who may need specialized care provided in facilities. The Council will continue to pursue unanswered questions emerging related to the Sunland Center, children in nursing homes, and will keep the pulse on individuals with developmental disabilities and behavioral issues that result in their placement in IDF/IIDs.

- VII. To the extent that information is available, the adequacy of home and community-based waivers services (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c)))*:

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% was in the Medicaid HCBS category, and 22% in Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities, followed by 16% in other federal spending and 4% in other state Medicaid spending (Tanis, 2021). HCBS Waiver costs by fiscal year per participant in Florida were most recently reported at \$32,700 with a total of 35,073 individuals in the community who were active on Florida's iBudget HCBS Waiver as of June 30, 2020.

Data from the National Residential Information Systems Project (RISP) indicated that from 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. The waitlist for iBudget Florida waivers hovers above 20,000 individuals, while the 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).

Many data sets underscore the need for investments in HCBS in Florida. 75% of persons with I/DD live with a family caregiver. Only one-third, 33%, of persons with I/DD live with family caregivers under the age 41 and almost as many 31% 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 6% receiving support from APD.

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The 2017 legislative session resulted in \$3.4 million dollars of state general revenue to draw down a 60% federal Medicaid match for receiving HCBS iBudget Waiver funding and resulted in approximately 350 individuals coming off the HCBS iBudget Waiver waitlist. \$15.7 million was allocated for the Department of Labor hourly adjustment and provider rate increases were made, including \$4.4 million of this allocation for personal supports, residential habilitation, adult day training and supported employment rate increases, though these funds were non-recurring. \$750,000 was allocated for the Employment Enhancement Project (EEP) to fund employment internships and supported employment services to assist with bringing additional individuals off the waitlist.

In 2018, \$89.3 million was requested in HCBS iBudget Waiver Funding, but \$0 funding was allocated. Additionally, \$21.9 million was requested to serve additional clients on the waitlist, with \$0 funding allocated. \$1 million was requested for the Employment Enhancement Program, and \$900,000 was allocated. \$41 million was requested and obtained to maintain existing service rates partially funded with non-recurring funds from the 2017 General Appropriations Act. Requests were made for provider rate increases, but funding for rate increases were not addressed.

In 2019, the Florida House and the Senate expressed concerns about the HCBS iBudget Waiver and the challenge to contain the cost of the additional needs that waiver recipients need as they age or experience life changes. \$22 million was requested in HCBS iBudget Waiver funding, and \$18,842,000 million was allocated. \$15.8 was requested to serve additional clients on the waitlist, but \$0 was allocated. \$900,000 was requested and allocated for the EEP. HCBS Waiver rate funding was requested for personal supports in the amount of \$27 million, but \$0 was allocated. Waiver rate funding was requested for residential habilitation in the amount of \$16 million, and \$11 million was allocated.

In 2020, the Florida Legislature vetoed provider rate increases, but provided generous funding, including federal matching funds, for “Resources for Persons with Unique Abilities” in the amount of \$58,034,834; “Serving Additional Clients on the HCBS Waiver Waitlist” in the amount of \$30,223,451; and funding for the APD deficits from the past 2 years in the amount of \$241 million dollars.

In 2021, the Florida Legislature provided one of the largest funding increases to transition individuals off the HCBS iBudget Waiver waitlist in history! Florida lawmakers agreed to spend \$95 million a year to provide more people with intellectual and developmental disabilities access to services they need to live in their communities and out of institutions. Unfortunately, there were no provider rate increases.

Florida has experienced a 51% turnover in direct support providers and many providers have a critical number of vacancies for personal support staff. With the number of vacancies at these

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levels, there are critical concerns about meeting the needs of individuals with intellectual and developmental disabilities who are coming off the waitlist. There were no utilization increases for those who are on the HCBS iBudget Waiver who may have significant additional needs for more or different services. There was also no attempt to put any HCBS iBudget Waiver services into for-profit managed care in 2021.

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% since 2007 (Perkins, 2019). With inadequate funding for the HCBS iBudget Waiver services, exasperated by inadequate funding for direct service providers and compounded by COVID-19, many provider organizations have been forced to significantly reduce their services or close their doors.

Bold leadership and creative systems change efforts will be needed to thwart the further erosion of health, safety, and quality of life for persons with I/DD and those who care for them in Florida.