

Aging Generations' Expectations in Developmental Disabilities

Final Overall Report

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Florida
Developmental
Disabilities
Council, Inc.

124 Marriott Drive, Suite 203, Tallahassee, Florida 32301
(850) 488-4180; email: fddc@fddc.org; website: www.fddc.org

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Executive Summary

The Florida Developmental Disabilities Council, Inc. (FDDC) contracted with Margaret Lynn Duggar and Associates, Inc., to conduct a study and develop a roadmap to guide the FDDC's new 5-year state plan priority on Aging Caregivers. The purpose of the Aging Caregiver priority is to establish a collaborative among federal and state policy leaders and influencers in both the aging and developmental disability networks to address the needs of aging caregivers of individuals with intellectual and developmental disabilities (I/DD) and aging individuals with I/DD: the aging family with I/DD.

In preparation for the FDDC's multi-year initiative to identify ways to educate and support families of older caregivers and their aging adult children with I/DD, a survey was conducted, background materials were developed, and three summits were conducted with members of both the aging and developmental disability networks.

Aging Generations' Expectations in Developmental Disabilities summarizes the state of the state on both aging and developmental disability in Florida, identifies the key issues facing the aging family with an individual with I/DD, and provides an initial roadmap for a collaborative and systems change endeavor between the aging and developmental disability networks in Florida.

The report contains 11 recommendations:

1. Develop an interagency Memorandum of Understanding for all state agencies who are involved in the needs assessment, eligibility determination, and provision of care for aging caregivers and for their adult family members with I/DD.
2. Promote cross-network training for service providers and case managers.
3. Identify the challenges of expanding the infrastructure of agencies to serve the increased clients resulting from the elimination of waiting lists, including appropriate compensation and training for staff.
4. Plan for the aging of the caregivers providing most of the care for Florida's population with I/DD, with a focus on creative housing opportunities with appropriate supports for aging families.
5. Expand the availability of personal care services by investigating payment to caregivers for personal services to be provided under the family caregivers' oversight with a stipend model based on the Florida Home Care for the Elderly model.
6. Maximize federal funding opportunities under Medicaid to strengthen the direct service delivery systems in the community to promote deinstitutionalization.
7. Encourage future/advanced planning by aging caregivers via training and guidance to case managers on the variety of resources available to assist families in planning for the future.
8. Encourage the sharing of client information across state agencies to increase administrative efficiencies.

9. Propose a Florida Legislative Commission on Aging Caregivers and Families be established to plan for the increased housing, health, and community services that will be needed in the near future.
10. Identify the policies that could be revised to open the silos of aging and developmental disabilities and include developmental services with expanded case management for the family rather than the individuals served by different agencies.
11. Develop and secure funding for a project that is supported by the Agency for Persons with Disabilities, the Florida Department of Elder Affairs, and the Agency for Health Care Administration that serves the changing needs of older caregivers living at home with adult family member(s) with a developmental disability.

Aging Generations' Expectations in Developmental Disabilities

Introduction

The purpose of the aging caregivers' initiative, Aging Generations' Expectations in Developmental Disability (AGEDD), is to address the lack of appropriate supports and services for older family caregivers and their aging adults with intellectual and/or developmental disabilities (I/DD). This report will provide a background of the aging and developmental disabilities systems in Florida. Since both systems have different funding streams and infrastructures, the task will be to find components that intersect in a positive way to support a new generation of older persons with I/DD and their aging caregivers. These Florida residents require the same sorts of home-and community-based, long-term supports and services that have been the hallmark of the aging network for several years.

Florida's General State of the State

Florida has continued to grow during the pandemic with a 1.63% annual growth rate (an estimated 1000 persons move to Florida each day) and has a total of 22.2 million residents in 2021. The State is projected to have 5 million new residents by 2030. It is the third most populous state in the nation and has the oldest population of any US state with 19.1% estimated to be 65 years or older. Florida has attracted retirees and especially *snowbirds* for many years. Retirees are attracted by the lack of a state personal income tax and no inheritance tax. The US Census Bureau estimates Florida's population over age 60 will grow from the current 25% to 32.5% by 2030.

Not many of the people moving to Florida consider the services a person with I/DD is receiving in their home state and what may be parallel or available at all in Florida, nor are they considering what services they, as caregivers, may need in the future as they grow older. This is very important for both aging caregivers and their family members in need of assistance as they age in place. Florida relies more on local revenue to fund government than almost any other state, and sales taxes account for 81% of Florida's tax collections compared to a national average of 46%. The lack of a state income tax leaves Florida with less funding for support of health and human services.

The waitlists for persons with developmental disabilities and for persons who are aged and in need of long-term care services reflect Florida's underfunding of human services. In 2021, there are currently 22,718 individuals with I/DD on the Agency for Persons with Disabilities waiting list. In 2020, according to a Florida Senate staff report on the Florida Department of Elder Affairs, there were 58,426 persons on the Medicaid home- and community-based services waitlist for the aging. In addition, there are another 36,000 aging persons waiting for state general revenue funded Community Care for the Elderly services. Florida ranks 50th in its funding of long-term care for the aging population and 49th for services to persons with I/DD.

First Steps to Addressing the Purpose of the Project

An advisory committee was formed to participate in the analysis of the current systems for aging and for developmental disabilities and to identify the *stated* and future needs of aging caregivers and their adult children with I/DD who are also aging. The advisory committee includes key leaders in Florida representing the two systems of aging and developmental disability services (see Appendix A).

This aging caregivers' initiative has produced descriptions of Florida's aging network and the developmental disabilities framework of services and plan development (see Appendices B and C). The advisory committee held discussions on the similarities and differences of the two systems. For example, respite care is an important service funded as a home- and community-based service for caregivers of persons who are aging and for adults with I/DD. For the aging, it may be funded through Department of Elder Affairs' general revenue for Community Care for the Elderly or by Medicaid Home- and Community-Based Services with the services provided by contract providers. For the persons with I/DD who live in the community with their aging caregivers, the provision of respite care is a welcome support. But the need exceeds the availability of the service through the developmental disabilities system, and there is limited interaction between the two systems.

The aging caregivers' initiative held three summits over the summer of 2021. The first summit in mid-June began with a focus on aging caregivers of older family members with a developmental disability (see Appendix D). This was followed by a second summit with participants from the private and public sectors providing care management for persons with developmental disabilities, along with aging service providers (see Appendix E). Summit 3 convened national and state policymakers and advocates as well as advisory committee representatives (see Appendix F).

Part I: Project Purpose and Partners

According to the Florida Developmental Disabilities Council (FDDC), in 2017 there were an estimated 472,644 people with I/DD in the state of Florida; 75% (i.e., 352,726) of whom live with a family caregiver. Of the estimated 352,726 family caregivers, 32% (i.e., 110,955) were over the age of 60 years. These demographics influenced this initiative. The main purpose for summit participants, representing both developmentally disabled and aging populations, is to help identify the most important issues and services that persons with I/DD and their family caregivers need as they both advance into their 60s and on into old age.

The FDDC operates under the federal Developmental Disabilities and Bill of Rights Act of 2000 and was established under Chapter 393 F.S., Governor's Executive Order 95-478 in 1995. Approximately \$4 million annually in formula funded appropriated federal funds is provided to the FDDC through the Administration for Community Living (ACL), whose fundamental principle is that older adults and people of all ages with disabilities

should be able to live where they choose, with the people they choose, and with the opportunity to participate fully in their communities. The main requirement under the federal Developmental Disabilities Act of the FDDC's Governor appointed Council is to leverage federally appropriated dollars to facilitate major systems change; affect policy; build capacity within existing and future delivery systems; and advocate with, and on behalf of, individuals with I/DD. The FDDC is the only funded, independent entity in Florida with the authority to facilitate collaborative partnerships among all state agencies, universities, and disability organizations, and has the designated authority to advocate with the Executive branch and the Legislature. <https://www.fddc.org/>

Aging families and caregivers of persons with I/DD have been identified as one of the top five concerns in Florida by the FDDC. This growing concern led to the contract with Margaret Lynn Duggar and Associates for an aging caregivers' initiative, including workgroups and three summits to strategize together how to address identified needs. This initiative focuses on the identified and projected needs of aging caregivers and their adult children with I/DD today and over the next 5 years.

The Florida Agency for Persons with Disabilities (APD) is responsible for services for persons who meet the statutory definition of developmental disability; "a disorder or syndrome that is attributable to intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, Phelan-McDermid syndrome 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 (393.063(12) F.S.). The APD is responsible for the home- and community-based services waiver (i.e., iBudget) for services. Application is made to the local APD office by mail or in person or online at <http://apd.myflorida.com/customers/application>

The APD maintains the state-wide waitlist of individuals waiting for waiver services. Enrollment in the iBudget waiver is available only when APD has determined it has sufficient funding appropriated to offer enrollment to an individual, when a review of the individual's diagnosis and related characteristics indicate that the Intermediate Care Facility for the Developmentally Disabled level of need (i.e., criteria) has been met, and when a determination of Medicaid eligibility has been made.

The Florida Department of Elder Affairs is responsible for the 11 Area Agencies on Aging and the Aging and Disability Resource Centers across Florida. In accordance with the federal direction from the ACL, the Aging and Disability Resource Centers serve as a single intake point for aging persons and for persons with I/DD. The resource centers provide information on state and federal programs as well as local services, including Medicaid eligibility and directions for application. The Older Americans Act, general revenue, and Medicaid waiver are the funding sources for a range of aging services.

The Department of Children and Families is responsible for the Medicaid eligibility determination process.

The Agency for Health Care Administration is responsible for the state Medicaid program, including the financing and regulatory oversight.

The Administration for Community Living is the federal agency whose fundamental principle is that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the opportunity to participate fully in their communities. The ACL oversees the Older Americans Act appropriations and distributes them to each state based on a formula to implement services prescribed in the Older Americans Act. The ACL also oversees the Developmental Disabilities and Bill of Rights Act appropriations, which are distributed to each state based on a formula to implement DD Councils (i.e., planning and coordinating), University Centers for Excellence in Developmental Disabilities (i.e., research) and Protection and Advocacy (i.e., civil rights). No dollars can be used for direct services. Hence, any I/DD funded services are either through the State's Medicaid state plan or Medicaid home- and community-based service system.

Part II: Aging Caregivers' Initiative Parameters and Research Results

Summit participants have included leaders from both the aging and developmental disabilities fields of research/education, policy making and practice, and caregiving. University affiliated representatives have provided ongoing insight into best practices and research. Policy makers and advocates have provided an understanding of the funding challenges and unmet needs throughout Florida for persons in need of services through the aging services network and for developmental disabilities services. Caregivers have shared their fears for what the future holds for aging caregivers and their aging children with I/DD.

Important input from the initiative is reflected in the repository of best practices and models as well as research results collected for the advisory committee and summit participants (see Appendix K). Through the ACL, many states and the federal government have participated in special projects to promote adult family caregiving. For example, the Center for Health Care Strategies has released papers describing several different states' efforts to support family caregivers. A *Snapshot of Five States* showcases Hawaii's financial support for daycare for aging caregivers to be able to continue working, and Tennessee has been notable for mandating their Medicaid managed care providers to assess family caregivers with in-person assessments to cross the silos of care for aging and for persons with developmental disabilities. Many states have begun projects for incorporating family caregiving supports as an integral component across home- and community-based services.

The national initiative, *Helping States Support Families Caring for an Aging America*, is working with state and private organizations to partner around Medicaid, aging and human services, the Area Agencies on Aging, universities, health plans and community-based organizations to advance family caregiving programs. The Center for Health Care Strategies has worked with 14 states around the following key strategies:

- Strengthen family caregivers' capacity through new technologies, increased access to respite care, and increased formal training for family caregivers.
- Establish data systems to better inform policy makers and advocates with more robust data collection efforts.
- Build formal cross-sector partnerships and strategies across aging, housing, transportation, health plans, and developmental disabilities to support family caregivers.

One of the successful cross-agency efforts has been with Virginia's Department of Medical Assistance, partnering with both aging and developmental services to access data for service utilization by Medicaid enrollees, and to identify those who may become Medicaid-eligible across programs. This allowed all agencies to share data and reduce duplication of efforts in eligibility determination and assessments. The state of Iowa developed a uniform family caregiver assessment tool for the Area Agencies on Aging.

The American Association of Retired Persons report, *Aging and Disability Resource Center/No Wrong Door Functions*, included successful state efforts to build intentional partnerships and quality improvement in person-centered counseling for individuals with I/DD and family caregivers. Georgia successfully implemented a state-wide Aging and Disability Resource Center Advisory Council with representatives from aging and the 12 Area Agencies on Aging, the Medicaid agency, Department of Behavioral Health and Developmental Disabilities, the state Independent Living Council and Centers, and the Brain Injury Association. All partners now use the same data system to collect and share data including demographic and assessment information.

The American Network of Community Options and Resources (ANCOR) is a national, nonprofit trade association of over 1,600 private community providers of services to people with disabilities. A national report by ANCOR, *Case for Inclusion 2020*, reported that almost half a million people were on waitlists for community services in 2017. The report faults low wages as a cause of the high vacancy rates and the high turnover in the frontline positions. The report emphasizes the significant needs that people with disabilities and their caregivers are increasingly facing from the decades of underinvestment in long term supports and services for people with I/DD.

The Disability and Aging Collaborative (DAC) includes 40 national organizations formed in 2009 to support long-term services for older adults and persons with developmental disabilities with a focus on increasing Medicaid home- and community-based services and rebalancing Medicaid funding from institutions to the community. The DAC is led by the National Council on Aging and The ARC of the United States.

The Rosalynn Carter Institute for Caregiving published October 2020 survey results of primary caregivers, where 83% reported increased stress related to caregiving during the COVID-19 pandemic with activities being curtailed and services reduced. Caregivers reported an increased burden from added caregiving responsibilities with the decline of formal and informal services and assistance. The financial stress of meeting the day-to-

day needs of the care recipient and financial barriers in planning for the future were raised by many caregivers.

Part III: Major Findings From Florida's 2021 Online Survey of Aging Caregivers

Currently there are no proper services provided for the developmentally disabled, making it necessary for the aging parent to play this role. As an aging parent, this is not sustainable. I am not aware of any provisions made by APD to provide the required comprehensive services needed by aging developmentally disabled individuals.... they are living longer and likely will outlive their parents. The State is not prepared and is not allocating the necessary funding to create the plan and establish it. (see Appendix H)

The survey of aging caregivers was developed by the FDDC to collect caregiver and recipient state-wide information on those with I/DD (see Appendices H, I, J). The survey results indicate a majority of caregiver respondents (i.e., 51.9%) are between the ages of 60 and 70 with another 27% over age 70. *Eighty-two percent (82%) of the adult children with I/DD live with their caregivers in family homes while the remaining 18% live in their own homes, group homes or assisted living facilities.*

Duval County led the counties with 7.5% of respondents, followed by Broward, Orange, Hillsborough, Marion, Pinellas, Brevard, Palm Beach and Polk. Miami/Dade rounded out the top 10. The rural counties had limited representation with 24 rural counties having no respondents.

I have a hard time just taking care of things around the house because of my health and my enjoyment in life is at a major low point because I just cannot be and do everything like I used to be able to do. I remember meeting other older moms, when I was younger, hearing them express that they had gone downhill. (see Appendix H)

From the survey responses, it is not possible to determine the service intensity needed by the care recipients or the caregivers, only the percentage of respondents who currently receive each service. For example, case management/care coordination is the most frequent service provided at around 80%, and companion/aide to take the person into the community ranks second at 31.6%. The third ranked service is personal care attendant and adult day care is fourth. Transportation is the fifth ranked, followed by respite care, therapies, counseling, and nursing.

I no longer can care patiently. I am not a safe driver, on pain pills for chronic pain. He has not had adult day services since pandemic. I am depressed and overwhelmed. We were on the waiting list for 16 years before we got any help. The so-called services have been inadequate and unreliable. Still feel his total care needs are all on me....Florida should be ashamed of the way that this dependent population is treated. (See Appendix H)

Services Needed in the Future

The responses from the aging caregivers note the importance of case management with almost 70% recognizing the continued need in the future. The companion/aide anticipated future need doubles from 31% to almost 60%, personal care need rises to 51.6%, transportation from 15% to 51%, respite care from 15% to 47%, adult day care from 27% to 43%, with the following services increasing to 33% – 37%: wellness, therapies, counseling, and personal emergency response.

Home delivered meals, a service reported for less than 1% of persons with developmental disabilities during the time of the survey, are anticipated to grow to 24.4% for recipients of care. Additional service needs were identified in the areas of guardianship, financial management assistance, and needs for different types of housing including supported living in a residential community. The anticipation of such growth in service needs in the future are also reflected in the comments, such as:

As I get older, how will I pick him up and transfer him? My back is already pinched in six vertebrae. How do I keep this up? (see Appendix H)

Been on APD waitlist for 15 years. He's now an adult. Need waiver program assistance soon (see Appendix H).

Fear of me and my husband dying and leaving our autistic adult twins without appropriate housing and care (see Appendix H).

There were many comments related to the caregiver dying or becoming disabled and unable to continue caring for the person(s) and not having an alternative caregiver. Caregivers recognize the major role they have in ensuring care is provided, either by themselves or with intermittent assistance when services are received.

Who will take care of my child and make sure he is safe and healthy when I am no longer able to? How long will I be able to care for him? It gets physically and mentally exhausting to fight for and justify everything (see Appendix H).

How to Access Services

Respondents were divided in roughly thirds when asked if they know where to access information on future service needs with 37.7% reporting *they did not know*, another 34% responding *yes* and 28% *maybe*. Approximately 52% of caregivers said they are not familiar with the local Area Agency on Aging and ADRCs or what they do while 30% said they were familiar and 18% were not sure.

When asked *Are you on a waiting list for services?* almost 80% said *No* and 14% *Yes*, with the remaining 6% responded *Unsure*. The responses present a profile of a third of the caregivers informed of the local Area Agency on Aging and knowing where to get information about future services. The caregivers acknowledged that 10% of them have applied for aging program services for their adult children, but they have not been successful because the adult children are receiving services from the iBudget waiver

Caregivers' Wishes

When asked If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be? the vast majority commented on the need for services, for qualified staff, and for less bureaucracy in trying to access services with more assurance of ongoing services.

The following were also frequent replies:

Fair wages to attract qualified personal care and supported living staff (see Appendix H).

Better pay for APD's Direct Service Providers so the staff openings can be filled, and staff will stay. New staff all the time is not good for a person with ID/DD (see Appendix H).

Summary of Aging Caregivers' Responses

Most caregivers who responded to the online survey are aging in place in their own homes with their adult child who has I/DD, who is also aging into their middle and older age. Services are limited but aging caregivers and their care recipients want to remain in their own homes as long as possible. Problems are noted with having trained, quality staff who are paid enough to remain in their jobs providing I/DD services in the community. The continuity of care is viewed as the responsibility of the primary caregiver, but there are major concerns about their becoming ill and dying in the future. What will happen to their loved one?

Part IV: Brief Critique of the Organizational Structures of the Aging and Developmental Disabilities Networks

The advisory committee for this initiative reviewed the organizational structures of the two separate systems for how they interrelate, whether at the point of entry through the Aging and Disability Resource Centers, or how they operate between different service silos. Aging caregivers and their adult children who are aging with I/DD have needs that often cross the two systems. A major consideration is the opportunity to remain in the community and out of a nursing home or a residential facility whenever possible.

Aging Network: The Florida Department of Elder Affairs

The Department of Elder Affairs is responsible for the 11 Area Agencies on Aging and ADRCs across Florida. In accordance with the federal direction from the ACL, the ADRC is to serve as a single intake point for aging persons and for persons with developmental disabilities. The ADRC provides information on state and federal programs as well as local services. The ADRC will inform on Medicaid eligibility and directions for application.

The managed care takeover of Medicaid nursing home- and community-based services over the past decade has resulted in increased complexity in eligibility and service accessibility. An initial Medicaid eligibility based on income and assets determines if the person is referred to Medicaid home- and community-based services through managed care. There are now two systems for the aging services with managed care over one and the Aging Network overseeing the other. The screening intake is by phone and therefore limited. It can be confusing to the caregiver and the client looking for services.

The primary decision point for aging services is at entry with an initial eligibility screening and encouragement for a Medicaid eligibility application to be submitted. Community Care for the Elderly is general revenue funded for low-income persons who are not Medicaid eligible but at risk of nursing home placement, with case management and other services such as adult day care, respite care, home delivered meals, personal care, medical supplies, light housekeeping, and minor repairs.

A second and very important decision point is with the Comprehensive Assessment and Review for Long Term Care Services (CARES) process of determining if a Medicaid eligible person meets the requirements for institutional placement for both the aging and persons with I/DD. A CARES is given to persons who are Medicaid eligible and, if determined at risk for nursing home placement or an institutional placement through APD, are referred to the Medicaid waiver Managed Care system for community-based services.

Older Americans Act (OAA) funding is primarily targeted through the DOEA for nutritional programs and social activities through senior centers and congregate sites, although local aging providers also use OAA funds to provide in-home meals, personal care and caregiver supports. Advisory committee members discussed experiences with aging persons who have I/DD participating in senior center activities that are OAA funded.

Developmental Disabilities: The Agency for Persons With Disabilities

The Agency for Persons With Disabilities is responsible for the Medicaid home- and community-based services waiver. Applications for services are made to the local APD office by mail, in person, or online. The APD maintains the state-wide waitlist of individuals waiting for waiver services.

At the time of application for the iBudget Waiver, a person must already be Medicaid eligible, or apply or have a designated representative apply for Medicaid benefits through the Department of Children and Families. Caregivers mentioned the complexities of the iBudget process used to determine individual amounts of services.

Enrollment in the iBudget Waiver is available only when APD has determined it has sufficient funding appropriated to offer an enrollment to an individual, when a review of the individual's diagnosis and related characteristics indicate that the Intermediate Care

Facilities/Developmental Disabilities level of criteria has been met, and when a determination of Medicaid eligibility has been made.

The iBudget rule established in 2016 created a new algorithm for individuals enrolled in the iBudget Waiver program (65G-4.0213 – 4.0218 FAC). Florida has a complex algorithm as the starting point in determining the person's iBudget amount. Waiver support coordinators (WSCs) are responsible for working with individuals and caregivers on their caseloads by making sure that services meet their needs. During the review, the WSC discusses the allocation algorithm amount with the individual, or individual's representative and, if applicable, the client advocate. The APD determines whether services requested meet health and safety needs and waiver coverage and limitations.

The APD issues a decision regarding the iBudget amount within 30 days of receipt of the Amount Implementation Meeting (AIM) Worksheet. The Notice of iBudget Amount includes information on how the iBudget amount was determined. If an individual believes the APD's action is erroneous, a mistake, or otherwise wrong, there may be an appeal to an administrative hearing before the Office of Appeal Hearings, Department of Children and Families, to dispute the decision. Consumers have some flexibility with the iBudget program to move money to different services should their needs or goals change. The Significant Additional Needs (SANs) assessment gives consumers in the Medicaid iBudget Waiver program, an opportunity to provide a rationale for an increase in services, which APD will then consider.

Part V: Immediate Needs vs. Planning for the Future

Who will take care of my adult child and make sure he is safe and healthy when I am no longer able to? How long will I be able to care for him? How can I continue to advocate for every single thing he needs to be safe and stay in his community? It gets physically and mentally exhausting to fight for and justify everything. It seems there are more and more layers of paperwork and bureaucracy for my son to receive any help. (see Appendix H)

The advisory committee included many caregivers of persons with I/DD and advocates with long histories of experience in direct care as well as highly regarded professional experience in education, research, administrative oversight of aging and developmental disabilities' networks, case management and other service programs (see Appendix A). The advisory committee meeting participants emphasized the challenge to get Floridians in the general population to see the hidden communities of people on waitlists and in need of services. Funding increases are needed to meet the needs represented on the waitlists today. The advisory committee members carefully reviewed and discussed the aging caregivers' survey results, where there were many comments about in home services' staff having high turnover and concern about the need to increase the wages of frontline staff.

Advisory committee members proposed that future innovative housing needs for aging persons with developmental disabilities are needed. A model of assisted living was

identified that would be akin to today's aging retirees' assisted living opportunities. The issue would be obtaining financing such as Housing and Urban Development federal funds and motivating companies in the private sector to work together for creating targeted housing in the future to meet the needs as aging caregivers' health declines. There are models for consideration, such as Independence Landing in Tallahassee, that has been in the planning process for 3 years and is now moving forward.

Summary of Summits I, II, and III

The advisory committee meetings and analyses of the online survey influenced the invitation of experts to the three Summits (see Appendix D for Summit I, Appendix E for Summit II, and Appendix F for Summit III). The first virtual summit held on June 15, 2021, by Zoom included many aging caregivers with much discussion on the basic needs of each day. The summit participants talked about the struggles assisting with daily routines that aging caregivers have with their loved ones. One of the components of care management is the educating of the caregiver. But all the duties and aspects of case management are not the same for all. Participants agreed that different forms of case management are needed, based on the age of families and the needs of the persons with developmental disabilities. The highly experienced caregivers participating in the first summit are very supportive of the care coordination services currently being provided, but indicated their concern is about when they will no longer be able to provide the primary care for their loved ones.

There were many survey comments related to the caregiver dying or becoming unable to continue caring for the person and not having an alternative caregiver. Advisory committee members recognized the increasing needs for advance care planning.

On June 29, 2021, the second summit participants reviewed the online survey results with an in-depth discussion of care management and the two parallel systems for the aging network and the programs for persons with I/DD. Approximately 51% of the survey respondents reported receiving services. Approximately 30% of the survey respondents are aging caregivers of adult children with autism.

There were significant differences between services received now and those that are anticipated for the future. For example, the need for home delivered meals is anticipated to increase in the future although it is not presently a very common service.

Participants were uncertain about how to integrate the two unwieldy service systems for aging and for developmental disabilities. Both have long waitlists for services under Medicaid waivers for home- and community-based services (i.e., Aging and DD) as well as for aging general revenue funded programs. Examples of restrictions were discussed when some I/DD care workers are concerned about helping an aging parent when in the home providing services for an adult with disabilities. Policy changes and cross-agency training were raised as viable possibilities to facilitate care for the aging caregiver.

My adult son needs a residential community with supported living services for growth and social engagement and integration into a community. We are very isolated in my old age (see Appendix F).

The proceedings of the first two summits were shared with the invited participants for the third summit on August 27, 2021, which included national and state leaders in policy making for aging and for persons with I/DD. Their input was recognized as very important for the work of this aging caregivers' initiative to provide a road map for the launching of a 5-year plan this fall. The input of national and state leaders, caregivers, policy makers and advocates are integral to the plan development and implementation.

Two representatives participated in Summit III from the federal Administration for Community Living, Costas Miskis and David Jones. David Jones, Director of the Office of Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services (DHHS) worked in two federal agencies focused on disability employment and programs prior to moving to ACL in July 2020. Costas Miskis, ACL Regional Administrator with Region IV, worked as legal counsel for the Florida Agency for Health Care Administration and the DOEA prior to joining the Region IV Department of Health and Human Services (DHHS).

Their discussion began with the federal focus on COVID-19 and recognition of the terrible impact on seniors with one third of the COVID-19 deaths in U.S. nursing homes. Nursing home residents represented only 4% of the COVID-19 cases but 31% of the COVID-19 deaths. The need for continued vaccination of nursing home residents and the nursing home employees is being focused on at the DHHS.

COVID-19-related relief is a part of the American Rescue Plan (ARP) signed into law in March 2021, the fifth COVID-19 relief package, totaling \$1.9 trillion. The law provides to states \$360 billion in aid with a number of additional provisions to improve access to health care and increase economic security for older adults during the pandemic. The stimulus payments included in this plan do not affect eligibility for Medicaid, SSI, or food stamps (SNAP). The ARP also distributed \$65 billion directly to counties based on population (see Appendix G).

For Aging and Disability Services specifically, the law provides \$1.4 billion increased funding for programs under the Older Americans Act: including \$750 million for home delivered meals; \$460 million for supportive services such as personal care, chore, and including COVID-19 vaccine outreach and coordination and efforts to address social isolation; \$25 million for services for Native American communities; \$44 million for evidence-based health promotion and disease and falls prevention programs; \$145 million for the National Family Caregiver Support Program; and \$10 million for the Long-Term Care Ombudsman Program.

Florida's Funding From the American Rescue Plan

According to the Florida Policy Institute, ...Florida will receive approximately \$10.23 billion, counties will get \$4.17 billion, metropolitan cities will receive \$1.47 billion, and other local governments will receive \$1.4 billion. Furthermore, the State is poised to receive about \$364 million for construction projects directly enabling work, education, and health monitoring in response to the pandemic. Lastly, stimulus checks, assistance for public schools, childcare, and unemployment benefits; additionally, it increases SNAP benefits, expands the Earned Income Tax Credit, and offers \$3.5 billion if Florida expands Medicaid.

The Agency for Health Care Administration (AHCA) submitted the Home and Community-based Services Spending Plan and Narrative to the Department of Health and Human Services in July 2021. AHCA Secretary Simone Marstiller, the Secretary of the Department of Elder Affairs, Richard Prudom, and the Director of the Agency for Persons with Disabilities, Barbara Palmer, participated in Summit III and discussed the Florida plan for the American Rescue Plan funds. Each of their agencies participated in the plan development and includes the following:

- A onetime stipend to all Home- and Community-based Service providers for distribution to their workforce. The stipend is proposed for both managed care and fee-for-service providers to encourage hiring and retention of workers.
- A onetime payment to persons 60 and older participating in a public assistance.

Summits' Recommendations

The three summits resulted in much increased interest and concern over the growing needs of aging caregivers who are in the community and providing care for their aging care recipients with I/DD. The bringing together of representatives from both the aging and the I/DD systems provided opportunities for envisioning a stronger framework of care around the family unit. A critique of the current systems and suggestions for how to facilitate communication and understanding resulted in recommendations for cross-training at the point of entry and ongoing throughout both systems. The unnecessary duplication of case management by two systems in the same family was discussed and strategies for improving the ability of case managers to better meet the needs of the family unit were explored. The infusion of American Rescue Plan funds was viewed as potentially giving caregivers access to increased services in the future. The state agencies' workgroup consists of the AHCA, DOEA and APD. Participants will continue to meet monthly for increased coordination and for the implementation of the ARP funding.

Part VI: Summary

The aging caregiver initiative has brought together many people who are personally involved as aging caregivers of persons with I/DD; as leaders involved in the delivery systems; as appointed policy makers in Florida and at the federal level; and as advocates for the growing needs of aging families. A majority of the caregivers who responded to the online survey, or who were participants on the advisory committee and on the summits, are aging in place in their own homes with their adult children who have I/DD and who are also aging. Appropriate services are limited. The waitlist for community-based services is a slow-moving process. Problems exist with having insufficiently trained, quality staff who are paid enough to remain in their jobs providing services in the I/DD community. The continuity of care has been viewed by the system as the responsibility of the primary caregiver, but with aging, major concerns arise about their becoming ill and dying in the future. The ubiquitous question, literally voiced by all: “What will happen then to their loved one?”

The important questions have been raised and recommendations have been made to streamline the bureaucracy and facilitate communication across state agencies that serve aging families consisting of older caregivers and aging adult children with I/DD. There is a recognized need for increased funding across human services in Florida by the state’s 51st ranking for its long-term care aging system by the AARP and 49th in services for persons with I/DD.

The American Rescue Plan will provide an infusion of funding for this fiscal year. The state of Florida has proposed one-time stipends to providers for distribution to staff to encourage hiring in direct care positions and retention. Many aging caregivers noted their concerns with staff turnover and low morale due to low pay. The new federal funding will alleviate some of the concerns in 2021-22.

The Agency for Health Care Administration is partnering with other state agencies to develop and implement a system that will assign one identifier to a person across all programs. The intent is to reduce the silo effect of stand-alone agencies simultaneously serving separate members of the same families, as with the aging caregiver of an adult child with I/DD. Hopefully the result of the new identifier will be a reduction in duplicate paperwork and service bureaucracy.

The identification of major needs being faced today by aging caregivers and their anticipated needs of the future for themselves, and their adult children, will provide the framework for the 5- Year Plan, beginning with the following:

1. Develop an interagency Memorandum of Understanding for all state agencies that are involved in the needs assessment, eligibility determination and provision of care for aging caregivers and for their adult family members with I/DD.
2. Promote cross-network training for service providers and case managers.

3. Identify the challenges of expanding the infrastructure of agencies to serve the increased clients resulting from the elimination of waiting lists, including appropriate pay and training for staff.
4. Plan for the aging of the caregivers providing most of the care for Florida's population with I/DD with a focus on creative housing opportunities with appropriate supports for aging families.
5. Expand the availability of personal care services by investigating payment to caregivers for personal services to be provided under the family caregivers' oversight with a stipend model based on the Florida Home Care for the Elderly model.
6. Maximize federal funding opportunities under Medicaid to strengthen the direct service delivery systems in the community to promote deinstitutionalization.
7. Encourage future/advanced planning by aging caregivers via training and guidance to case managers on the variety of resources available to assist families in planning for the future.
8. Encourage the sharing of client information across state agencies to increase administrative efficiencies.
9. Propose a Florida Legislative Commission on Aging Caregivers and Families be established to plan for the increased housing, health and community services that will be needed in the near future.
10. Identify the policies that could be revised to open the silos of aging and developmental disabilities and include developmental services with expanded case management for the family rather than the individuals served by different agencies.
11. Develop and secure funding for a project that is supported by the Agency for Persons with Disabilities, the Florida Department of Elder Affairs and the Agency for Health Care Administration that serves the changing needs of older caregivers living at home with adult family member(s) with a developmental disability.

Appendix A
Advisory Committee Members

Advisory Committee Members

Jessica Ayers MS, BSW, The Retreat Director
Council on Aging of West Florida, Inc.
875 Royce Street
Pensacola, FL 32503
Phone 850-432-1475 Ext 180
Direct office line: 850-266-2503
Cell Phone: 850-454-9234 **
jayers@coawfla.org

Jessica Ayers, MS, BSW, Retreat Director with the Council on Aging of West Florida in Pensacola. Ms. Ayers related her professional experiences with aging services for the past 26 years and personally with developmental disabilities since her young son has autism and her teen daughter has hearing deficits.

Andrea V. Busada, Director
Broward County Elderly and Veterans Services Division
2995 North Dixie Highway
Oakland Park, Florida 33334-2640
Office: 954-357-6622
ABUSADA@broward.org

Andrea Busada, Director of the Broward County Elderly and Veterans Services Division, is the immediate Past President of the Florida Association of Aging Services Providers (FASP), and is Treasurer of the Florida Council on Aging (FCOA). Prior to working in her current position, she worked for Broward County Paratransit for 10 years.

Larry Dixon
777 Duart Dr
Orange Park, FL 32073
Cell: 904-254-5270
soupbone@comcast.net

Larry Dixon, from Orange Park, worked for 28 years with the City of Jacksonville's senior services. After leaving the City, he worked for 15 years as a support coordinator. He served as President of the Florida Association of Senior Centers and recently on the AARP Executive Council, the Florida Association of Aging Services Providers (FASP). Larry Dixon briefly discussed his success at bringing persons with developmental disabilities into the Senior Centers for activities.

Kristen Griffis, Executive Director
Elder Options
100 SW 75th Street, Suite 301
Gainesville, FL 32607
352-378-6649
griffisk@agingresources.org
President of Florida Association of Area Agencies on Aging

Kristen Griffis, CEO of Elder Options for north-central Florida in Gainesville, has worked with the Area Agency on Aging (AAA)/Elder Options for 21 years with responsibility for all of the Department of Elder Affairs funding for services. The AAA's area covers the Villages as well as large rural areas. Her agency administers the Medicaid wait lists for community services and runs a multicounty helpline with over 16,000 calls annually for triage. Kristen Griffis acknowledged that Elder Options does not work much with persons with developmental disabilities although they had a grant a couple of years ago to work on a manual for integrating the two communities.

Lou Ogburn
3263 Robinhood Rd
Tallahassee, FL 32312
850-385-7400
Cell: 850-933-0956
louo@comcast.net

Lou Ogburn is the parent of a 55-year-old daughter who lives in her own home with an assistant daily arriving at 4 p.m. for the evening because of possible epilepsy. Lou Ogburn shared her 24 hour a day availability for her daughter. Her husband died the previous November.

Elizabeth A. Perkins, PhD, RNLD, FAAIDD, FGSA
Associate Director and Research Associate Professor
Florida Center for Inclusive Communities/UCEDD
Department of Child and Family Studies
College of Behavioral and Community Sciences
University of South Florida
13301 Bruce B. Downs Blvd, MHC 2113A
Tampa, FL 33612-3807
813-974-7076
eperkins@usf.edu

Liz Perkins, Ph.D., RNLD, Associate Director and Research Associate Professor, Florida Center for Inclusive Communities, Department of Child and Family Studies, College of Behavioral and Community Sciences, University of South Florida (USF), Tampa, is originally from the United Kingdom and was a nurse in geriatric disabilities before moving to USF for a Ph.D. in Aging Studies. Liz Perkins has been a member of the DD Council for over a decade and provides training and education on the needs and services of persons aging with developmental disabilities and aging caregivers. She acknowledged that research is limited in this area. She is an advocate on the iBudget and stressed the unmet needs of over 20,000 people on Florida's waitlist for DD services. This includes approximately 400 aging caregivers over the age of 70.

LuMarie Polivka-West, Sr. Research Associate
The Claude Pepper Foundation
636 West Call St.
Tallahassee, FL 32306
Cell: 850-556-9346
Email: polivkawest@yahoo.com

LuMarie Polivka-West is a volunteer researcher with the Florida State University Claude Pepper Center with 40 years experience in aging and Medicaid and long term care.

Jean Sherman, Ed.D., RN
Research Assoc. Professor
University of Miami
11306 SW 9th Court
Pembroke Pines, FL 33025
Cell: 954-707-1539
Email: jsherman@med.miami.edu; jeansherman75@yahoo.com

Jean Sherman, Ed.D. and RN, Research Associate Professor, University of Miami, is an aging caregiver of her 53-year-old son. She has a long history in nursing, health care coordination, aging and developmental disabilities including being the assistant director at the Broward Area Agency on Aging, appointments in both aging and developmental disabilities at the University of Miami, employment with the Landmark Learning Center and formed a gerontological nursing association in South Florida. Her PhD centered on aging and developmentally disabled persons. Jean Sherman noted that 25 years ago there was much success with leaders of aging services taking the advocacy lead to identify and serve aging parents of older people with developmental disabilities. However, advocacy and people's involvement declined as the funding declined.

Florida Developmental Disabilities Council:
Valerie Breen, Executive Director
Florida Developmental Disabilities Council, Inc. (FDDC)
124 Marriott Drive, Suite 203
Tallahassee, Florida 32301-2981
850-488-4180
Email: valerieb@fddc.org

Management Firm:
Margaret Lynn Duggar, President
Margaret Lynn Duggar & Associates
1018 Thomasville Rd, Suite 110
Tallahassee, FL 32303
850-222-0080
Email: mlduggar@mlduggar.com
Christina DeMeo
Margaret Lynn Duggar & Associates
1018 Thomasville Rd, Suite 110
Tallahassee, FL 32303
850-222-0080
Email: cdemeo@mlduggar.com

Appendix B

Understanding the Florida Aging Network: White Paper

Understanding the Florida Aging Network White Paper by LuMarie Polivka-West

There have been major changes in the Florida aging services network over the past decade with the managed care takeover of Medicaid nursing home and home/community based services. The state of Florida is divided into 11 geographic areas. Each has an Area Agency on Aging, which operates as the Aging and Disability Resource Center, and is the first point of contact for the client. The process begins when a client calls the Elder Helpline at 1-800-963-5337 to request an assessment. The client will be called back by a counselor, up to three times. If the client does not answer, a letter is sent but no other follow up.

During the phone assessment, the client, or their caregiver, are not instructed on what the questions mean or how the questions are ranked or scored for the total score for service eligibility. The Florida Department of Elder Affairs Form 701S, Screening Form, is a six page assessment and is used to determine if the person could be Medicaid eligible based on income and assets. This is important information for if the person is potentially eligible for Medicaid and if the application is not submitted, they are not considered for any other services such as Community Care for the Elderly (CCE) or Home Care for the Elderly (HCE) funded services.

The phone assessments are completed annually as long as the client remains on the waiting list. If there is no response, after three attempts, the client is taken off of all waiting lists. The lack of an in-person option is a problem because the person on the phone may not understand the questions being asked or they may overestimate their

ability to complete tasks, leading to an incorrect score/assessment. Furthermore, some clients may not have phones or computer access.

The screening assessment does not give any weight to the person (caregiver in this case) having memory loss or dementia nor whether the person (caregiver or the person with developmental disabilities) was in a group home or a nursing home in the last year. The question “Do you need assistance for food?” is also not included in the scoring, but the nutritional screen is to be completed for persons who respond “yes.” The problem is that a person with full dementia or an inability to take care of themselves and living alone in the community with no food, could be assigned a low level of “2” if they respond to all of the questions related to skills in such a way as not needing much help. The phone assessor may not be able to realize the problems.

Next Step: The completed screening form is submitted to the Department of Elder Affairs Client Information and Registration Tracking System (CIRTS). Individuals are advised to apply for Medicaid if the screening finds they meet the income and assets’ levels. The Comprehensive Assessment and Review for Long Term Care Services (CARES) is assigned the individuals who may meet the level of care for nursing home placement. Choice Counselors are available by phone or face to face appointment for sign up with a managed care provider after the person becomes Medicaid eligible, they meet the nursing home level of care or a slot for home and community based services becomes available and the person is at the top of the wait list for services.

Importance of Medicaid in Long Term Care

The caregiver has the responsibility to collect and submit all of the necessary forms and information for application to the Medicaid program. Before the managed care program, the aging network case manager would assist with the application process and would be available to answer questions and provide guidance through the process with CARES and links to services. If a client or their caregiver does not submit the Medicaid forms in a timely manner, then their case is closed. Previously, the aging services case manager was aware of each step of the process. Now with case management handled by the managed care providers and home and community based services provided by some of the aging services providers, the eligibility information is not shared. If the client is removed from services, the whole process has to begin again with the screening assessment, level of care, Medicaid eligibility and wait list assignment.

A person who is eligible for Medicaid may not be served with General Revenue (GR) services through CCE or HCE. Case management was previously the responsibility of the local elder care agency and clients were visited in their homes or in nursing homes or Assisted Living Facilities (ALF) quarterly with monthly phone calls. The managed care companies took over the case management responsibility and their process is primarily by phone and is conducted by nurses rather than social workers.

It is possible for a person who is referred through Adult Protective Services to move to the top of the wait list. The poor funding of the state's public guardianship program is a concern in Florida. A person in need of a guardian with no caregiver is a person at risk and may be referred through Adult Protective Services. In order for a person in the community to be able to go into a nursing home, two Assisted Living Facilities are

supposed to deny admission for the person. This is difficult in a community with limited ALF Medicaid beds.

There are now two systems where there used to be one with the wait list for services continuing to increase for home and community based services and strict parameters on nursing home placement. The screening intake system on the phone by the Area Agency on Aging is limited with no option for an in home assessment. Some clients may be assigned a low level on the waiting list because of misinformation reported by the caregiver who may have communication problems or may overestimate their abilities. The screening form does not include a weighting 4 for a person with dementia or cognition difficulties in determining the level. The case management system for the Medicaid Managed Care clients in the nursing homes and in the community is primarily via phone not face to face.

Community Care for the Elderly/Home Care for the Elderly/Older Americans Act

The case managers serving the CCE/HCE and other General Revenue and Older Americans' Act (OAA) funded client services are separate from the Medicaid Managed Long Term Care system. Long term clients receiving community based Medicaid funded services still contact the aging services case managers for assistance if they are unable to reach their assigned case manager with the managed care organization or they don't know who they are because of turnover. Other reasons include a reduction in their service plan for what they report on necessary services and/or a loss of Medicaid eligibility without the client's knowledge of what to do. Aging services case managers have assisted some of these clients in reporting complaints to the Agency for Health Care Administration but they in turn are passed on to the managed care organizations to handle. The Florida

Department of Elder Affairs' website describes each of the state funded programs of Community Care for the Elderly and Home Care for the Elderly and other community based services such as the Alzheimer's Disease Initiative (ADI). All of these state funded programs provide an array of community based services for caregivers from care management to shopping, transportation, home delivered meals, personal care and other services. The HCE program gives some caregivers a stipend of \$160 monthly to help keep loved ones in their home.

The federal Older Americans Act includes funding for congregate meals often at senior centers, home delivered meals, and supportive services such as transportation and case management and caregiver support with adult day care and respite care. The OAA funding is targeted somewhat 5 to the more rural communities with lower incomes as well as applicants experiencing the greatest decline in functioning.

Summary

Florida is one of the top states in the country in terms of its aging population. The AARP recently ranked Florida as 51st in its long term care system. What this means is that there continues to be a very large wait list of people in need of home and community base services across Florida in all of the state and federally funded programs due to needs exceeding the funding for care. The Florida legislative intent is to control funding increases as much as possible because there is no state income tax. Florida's low tax state status is one of the reasons that people retire here. However, when services are needed there is an aging network with experts who know the services that are available and how to help guide caregivers through what may seem to be a maze of different programs and requirements

Appendix C

The Sunshine State and Its Growing Needs of Persons With Developmental Disabilities

The Sunshine State and its growing needs of persons with Developmental Disabilities

An information brief by LuMarie Polivka-West March 29, 2021

Florida is one of the few states that has continued to grow during the pandemic with a 1.63% annual growth rate (an estimated 1000 move each day to Florida) and a total of 22.2 million residents in 2021. The state is projected to have 5 million new residents by 2030. It is ranked as the third most populous state in the nation and is the oldest US state with 19.1% estimated to be 65 years or older. Florida has attracted retirees and especially “snowbirds” for many years. Sumter County near Orlando is the oldest county in the US with 53% over 65 years of age, followed by Charlotte County with 38% over 65. Retirees are attracted by the lack of a state personal income tax and no inheritance tax. The US Census Bureau estimates Florida’s population over 60 will grow from the current 25% to 32.5% by 2030. Not many of the people moving to Florida are considering what services they may need in the future as they grow older. They are not informed of the serious underfunding of health and human services in Florida in the VISIT FLORIDA marketing materials.

A Montana mom asked in 2019 on the U.S. disabilities community board about possible Disney employment for her 19 year old son with intellectual developmental disabilities after high school graduation. She was planning to move across the country to Orlando for their small town had no job opportunities for her son and she thought Disney would “surely find something” out of all their jobs. The caregiving Mom wrote: “Statistics show that only 10% of DD people are employed and my son is in the bottom of the 10% with a 50 IQ, so I’m going against big odds here.... I’ve been planning this since he was born.”

Many people know Florida as the vacation site for Disney World (the world’s largest single employer in one location with 70,000 employees and 20 million visitors annually) and the 663 miles of beaches that bring over 100 million tourists each year. Tourism is the top industry but two thirds of the land is farmed, producing 70% of the world’s citrus and Florida is a major exporter of beef. It is important to recognize that Florida is largely a service economy based on tourism and agriculture. The state also has pythons in the Everglades, lots of alligators, big roaches, it is hot and the risks of hurricanes are real as well as the growing climate change impacts. However, the tourism promotional material stresses the sunshine and the current moderate climate and how friendly the state is for business with low personal taxes.

Florida has one of the largest economies in the US with tourism and agriculture, but it is not a generous state with services. Florida relies more on local revenue to

fund government than almost any other state and sales taxes account for 81% of Florida's tax collections compared to a national average of 46%.

The Centers for Disease Control and Prevention estimates that one in six children (15%) under the age of 18 are affected by a developmental disability with 5 million Americans of all ages affected nationally. According to the Florida Developmental Disabilities Council, in 2017 there were an estimated 472,644 people with intellectual developmental disabilities (IDD) in the state of Florida, 75% (352,726) of whom live with a family caregiver. Of the estimated 352,726 family caregivers, 32% (110,955) were over the age of 60 years.

This survey of Florida families confirms there is a growing number of aging caregivers with a third over 60. In FY 2017, only 6% (19,463) of the 352,726 family caregivers who had a person with IDD living in their home, received services from the Florida Agency for Persons with Disabilities. The number of these families receiving supports dropped 2.6% between FYs 2016 - 2017. As of February 2021, there were 22,700 individuals on a waitlist for IDD services. The average wait on the waiting list is reported to be 7 years.

The wait lists for persons with developmental disabilities and for persons who are aged and in need of long term care services are a reflection of Florida's lack of commitment to human services. There are over 65,000 on the Medicaid home and community based services wait list for the aging with disabilities and another 50,000 are waiting for state general revenue funded Community Care for the Elderly services. It is one of only 12 states that has not expanded Medicaid for its citizens without insurance. Most startling, Florida ranks 50th in its funding of long term care for the aging population with disabilities and 49th for services to persons with developmental disabilities.

Although Florida has the 17th largest economy in the world, it has a shrinking safety net as the population continues to skyrocket and to age. The budgetary decisions over the past decade indicate the lack of commitment to funding the needs. In 2019, there was only a reduction of 30 people on the waitlist for developmental services from the prior year according to the Florida Policy Institute. This year Governor DeSantis vetoed \$58.4 million in rate increases for community providers who care for persons with developmental disabilities and he deleted \$38.4 million in rate increases for institutional providers. The coming year is not much better. The Governor's proposal for 2021-22 recommends that only 300 more people with developmental disabilities be served and there is no recommendation to restore the previous budget reductions.

The Florida Agency for Persons with Disabilities (APD) is responsible for services for persons who meet the statutory definition of "a disorder or syndrome that is attributable to intellectual disability, cerebral palsy, autism, spina bifida,

Down Syndrome, Phelan-McDermid 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 (393.063(12) F.S.). The Agency for Persons with Disabilities is responsible for the home and community based services waiver (called the iBudget) and for placement in an intermediate care facility for the developmentally disabled (ICF/DD). Application for services are made to the local APD office by mail or in person or online at www.myflorida.com/accessflorida.APDa

Intermediate Care Facilities for the Developmentally Disabled

An intermediate care facility for the developmentally disabled (ICFDD) provides residential care for individuals with developmental disabilities with funding through the Medicaid program. ICFDDs are licensed and regulated by the state (Part VIII of Ch. 400, F.S., and Chapter 59A-26, F.A.C.). ICFDDs provide nursing services, activity services, dental services, dietary services, pharmacy services, physician services, rehabilitative care services, room/bed and maintenance services and social services. Individuals who have a developmental disability and who meet Medicaid eligibility requirements may receive services in an ICFDD.

Less than 2,000 people live in the 88 privately owned ICFDDs that report 97% occupancy. There are also 11 ICFDDs that are operated by the state. Prior to obtaining a license, the applicant must obtain certificate of need (CON) approval from the Agency for Health Care Administration (AHCA). Since Medicaid is the only payer, the CON requirement is used to manage the Medicaid provider network of ICFDD services. ICFDDs are considered institutional placements and are reimbursed for two levels of care, which are based on the client's mobility:

- **ICF Level of Reimbursement One-** for recipients who are ambulatory or self-mobile using mechanical devices and are able to transfer themselves without human assistance, but may require assistance and oversight to ensure safe evacuation; and
- **ICF Level of Reimbursement Two-** for recipients who are capable of mobility only with human assistance or require human assistance to transfer to or from a mobility device or require continuous medical and nursing supervision.

ICFDD providers in Florida have reported an increase in the number of residents with severe maladaptive behaviors that require significant resources to provide appropriate care beyond what is currently provided through the level one and level two-reimbursement methodology. Maladaptive behaviors are those behaviors that are disruptive, destructive, aggressive, or significantly repetitive. The legislature

had allocated additional funding this year for the increased care needs, but Governor DeSantis vetoed the \$38 million line item.

The Agency for Persons with Disabilities (APD) developed a Global Behavioral Service Need Matrix (Matrix) to classify the severity of a person’s maladaptive behavior for purposes of its home and community based waiver services, or iBudget, program, which is the Medicaid waiver program for persons with developmental disabilities.

The Matrix categorizes symptoms of maladaptive behaviors such as behavior frequency, behavioral impact, physical aggression to others, police involvement, property destruction, and elopement/wandering, among others. Each symptom is ranked on a scale of one to six, with one being the least severe and six being the most severe. If a symptom is not present, it is ranked as a zero. Based on a person’s behavior score, the person will be evaluated for services. The initial evaluation period is 12 months and then the frequency of evaluations afterwards depends on the severity of the person’s score, with a need level of six being evaluated more frequently than a need level of one. According to APD, 661 people within its iBudget program have higher level Matrix scores of 4, 5 or 6. The table below shows the average annual cost for individuals at these levels within the APD home- and community-based services program.

Global Behavioral Service Need Matrix Level Average Annual APD Cost

Level 4 \$132,777.73

Level 5 \$138,476.51

Level 6 \$158,823.46

Developmental Disabilities Individual Budgeting Waiver Services

The individual budget waiver (iBudget) for Developmental Services requires a person to meet the level of care criteria for placement in an intermediate care facility for individuals with intellectual disabilities (ICF/IID) and must be eligible for Medicaid. The iBudget rule established in 2016 the new algorithm for individuals enrolled in the iBudget Waiver program (65G-4.0213 – 4.0218 F.A.C.). The state has a complex algorithm as the starting point in determining the person’s iBudget amount. Waiver Support Coordinators (WSCs) are responsible for working with individuals and caregivers on their caseloads by making sure that services meet their needs. During the review, the WSC will discuss the Allocation Algorithm Amount with the individual, or individual’s representative and, if applicable, the client advocate. The Agency will determine whether

services requested meet health and safety needs and waiver coverage and limitations. The Agency will issue a decision of the iBudget Amount within 30 days of receipt of the AIM Worksheet form. The Notice of iBudget Amount will include information on how the iBudget amount was determined. If an individual believes the Agency's action is erroneous, a mistake, or otherwise wrong, there may be an appeal to an administrative hearing before the Office of Appeal Hearings, Department of Children and Families, to dispute the decision. Customers have more flexibility with the iBudget program to move money to different services should their needs or goals change. It gives them greater control over their lives.

Medicaid Eligibility

Individuals are eligible for Medicaid benefits through Supplemental Security Income (SSI), Medicaid for Adult Disabled (MEDS-AD), or Temporary Assistance to Needy Families (TANF). At the time of application for the iBudget Waiver, a person must apply or have a designated representative apply for Medicaid benefits through the Department of Children and Families (DCF).

The Agency for Persons with Disabilities maintains the statewide waitlist of individuals waiting for waiver services. Enrollment in the iBudget Waiver is available only when APD has determined it has sufficient funding appropriated to offer an enrollment to an individual, when a review of the individual's diagnosis and related characteristics indicate that the ICF/IID level of criteria has been met, and when a determination of Medicaid eligibility has been made.

The **Florida Department of Elder Affairs** is responsible for the 11 Aging and Disability Resource Centers (ADRC) across Florida. In accordance with the federal direction from the Administration for Community Living (ACL), the ADRC is to serve as a single intake point for aging persons and for persons with developmental disabilities. The ADRC provides information on state and federal programs as well as local services. The ADRC will inform on Medicaid eligibility and directions for application.

The **Agency for Health Care Administration (AHCA)** is responsible for the state Medicaid program, including the financing and regulatory oversight. AHCA is responsible for the Certificate of Need (CON) that is required for the ICF DD bed development.

The **Department of Children and Families** is responsible for the Medicaid eligibility determination process.

There are several organizations that address developmental disabilities advocacy

The **Florida Developmental Disabilities Council (FDDC)** was established in 1976 and administers up to \$3.6 million federal funds annually through the Developmental Disabilities Act to influence policy and create sustainable services and solutions for children and adults with developmental disabilities and their families through research support. The FDDC influences services in education, employment, transportation, and long term supports. The DD Council is the only funded independent entity in Florida with the authority to facilitate collaborative partnerships among all state agencies, universities and disability organizations. <https://www.fddc.org/>

Qlarant – the private, nonprofit Quality Improvement Organization (QIO) works with the APD and the Agency for Health Care Administration as the quality improvement and quality management contractor with the state of Florida (and Georgia and Virginia) with responsibilities for interviewing persons receiving services and assessing the provider network. Qlarant’s provider reviews are available for the past 18 months. Called a “provider discovery review” or PDR, the “performance scores reflect waiver rule-compliance based upon the number of standards reviewed.” <https://florida qlarant.com/>

The ARC of Florida – an advocacy organization that supports local chapters in providing education and information in support of persons and families. <https://www.arcflorida.org/>

FARF (Florida Association of Rehabilitation Facilities) an advocacy organization that advertises that it “is the only statewide advocacy organization that represents the CEO’s business, management and administrative interests in the rehabilitation arena in addition to our consumers and families.” FARF oversees the statewide program “RESPECT” that employs 1300 people with developmental disabilities in over 50 employment centers. <https://www.floridaarf.org/>

ABLE (Achieving a Better Life Experience) United created in 2015 to promote savings by families and friends of persons with developmental disabilities to help cover future living and health care costs. Up to \$15,000 annually may be saved as tax free and such savings may be disregarded in determining eligibility for Supplemental Security Income (SSI) or Medicaid. <http://www.abletrust.org>

Florida Developmental Disabilities Resources website is a public resource for persons with developmental disabilities and their families to link with providers who may best assist them in meeting their needs. [https://fddresources qlarant.com/html/contact us.htm](https://fddresources qlarant.com/html/contact_us.htm)

Appendix D

Aging Caregivers' Summit I



Aging Caregivers Summit

Tuesday, June 15th ~ 2:00 PM – 5:00 PM ET

To join using Zoom:

<https://zoom.us/j/94655204708?pwd=NGxQTzIwNUh5cTNuVk0dkd2dTUyUT09>

Meeting ID: 946 5520 4708~ Passcode: 733251

Dial by your location: 646-558-8656 US (New York)

The main purpose is for invited participants, representing both developmentally disabled and aging leaders, to help us identify the most important issues and services persons with developmental disabilities and their family caregivers need as they advance into their 60's and on into old age.

Agenda

2:00 PM Sherman	Welcome & Comments	Valerie Breen/Jean
2:10 PM	Brief Introductions	Everyone
2:30 PM Duggar	Aging Network Summary	Margaret Lynn
2:45 PM	DD Network Summary	Valerie Breen
3:00 PM	Aging Caregiver Survey Summary	Christina DeMeo
3:20 PM	Reactions to the Survey Responses	Everyone
3:45 PM	Break	
4:00 PM	Discussion of Caregiver Survey Responses, Aging & DD Networks & Available Services	Everyone
4:55 PM Breen/Margaret Lynn Duggar	Closing Comments	Valerie
5:00 PM	Adjourn	

Summit Materials can be viewed at:

https://drive.google.com/drive/folders/1SxRLs6Mxm_NZGV8esDcWVM0iqVh_e5HZ?usp=sharing

This Summit is being recorded.

Aging Caregiver Summit Participants

June 15th, 2021

Summit Invitees

Susan Byram
Co-Founder & Past President Autism Pensacola
Pensacola, FL

Ryan Chandler,
President, Support Coordinator Chandler Support Services, Inc.
Jacksonville, FL

Irene Klay
Tallahassee, FL

Pauline Lipps
Family Care Council Suncoast East Chair
Sarasota, Florida

Byron Stone
Stone Support Coordination, Inc.
Jacksonville, FL

Nancy Titcher
Tallahassee, FL

Ella Warren
Pensacola, FL

Mrs. La'Warren Williams,
WSC Stone Support Coordination, Inc.
Jacksonville, FL

Advisory Committee Members

Jessica Ayers MS, BSW, The Retreat Director
Council on Aging of West Florida, Inc.
Pensacola, FL

Andrea V. Busada,
Director Broward County Elderly and Veterans Services Division
Oakland Park, FL

Larry Dixon
Orange Park, FL

Lou Ogburn
Tallahassee, FL

Elizabeth A. Perkins, PhD, RNLD, FAAIDD, FGSA
Associate Director and Research Associate Professor
Florida Center for Inclusive Communities/UCEDD
Department of Child and Family Studies College of Behavioral and Community Sciences
University of South Florida
Tampa, FL

LuMarie Polivka-West, Sr. Research Associate
The Claude Pepper Foundation
Tallahassee, FL

Jean Sherman, Ed.D., RN
Research Assoc. Professor
University of Miami
Pembroke Pines, FL

FDDC:

Valerie Breen, Executive Director
Florida Developmental Disabilities Council, Inc. (FDDC)
Tallahassee, FL

Management Firm:

Margaret Lynn Duggar, President
Margaret Lynn Duggar & Associates
Tallahassee, FL

Christina DeMeo, Program Specialist
Margaret Lynn Duggar & Associates
Tallahassee, FL

Aging Caregivers' Summit Proceedings Summary

Tuesday, June 15, 2021 2:00 pm EST

“The main purpose is for invited participants, representing both developmentally and aging leaders, to help us identify the most important issues and services persons with developmental disabilities and their family caregivers need as they advance into their 60’s and on into old age.”

The Aging Caregivers Summit began at 2:03 p.m. with welcoming remarks by Valerie Breen, Executive Director of the Florida Developmental Disabilities Council, Inc. which was established in 1971 under the federal government in every state to leverage federal funds and provide advocacy. The Council facilitates advocacy with all partners, the Legislature and other executive branches. The work of this aging caregivers' initiative is to provide a road map for the launching of a five year plan this fall. The input of caregivers, policy makers and advocates will be very important to the plan development and implementation. This is the first of three Summits beginning with a focus on aging caregivers.

Jean Sherman, Ed.D., RN, Research Associate Professor at the University of Miami, welcomed participants noting that as an aging parent and a representative of one of two centers of excellence, the focus has traditionally been on young children and families with developmental disability needs. She said that “aging and developmental disabilities in the same sentence is rare” but interest first began at the turn of the century and “now we are in the midst of an aging tsunami.” Covid19 was noted to emphasize the confluence of factors affecting families and there is a growing universal recognition of family caregiving.

Margaret Lynn Duggar, President of Margaret Lynn Duggar and Associates, welcomed participants as the facilitator of the Summit proceedings and the contract work.

Each of the Summit's caregiver participants introduced themselves with a brief description of their respective caregiving roles as aging parents or as parents of younger children with developmental disabilities and responsibility for an aging parent with dementia. As one 76 year old caregiver said about her 48 year old daughter “I really worry about what will happen if I go first.” Liz Perkins PhD, Associate Director and Research Associate Professor of the USF Center for Inclusive Communities, a second center of excellence, referred to participants as “compound caregivers” involving aging and developmental disabilities.

Larry Dixon, recently retired as a Support Coordinator with a stepson with Asperger's 2 has a long history as an aging services advocate as well. Andrea Busada, Director of the Broward County Elderly and Veterans Services Division, and Margaret Hooper, the FDDC Director of Public Policy brought the expertise of aging related services to the discussion.

Margaret Lynn Duggar with almost 50 years of service in the field of aging as a previous Secretary of Elder Affairs under two governors beginning as the panhandle Area Agency on Aging Director, highlighted the importance of personal advocacy with the sharing of stories and the need to work together.

Valerie Breen, a clinical social worker with a forty year history in the field, stressed the need to build a network in Florida for Developmental Disability Services and Aging Services. According to the Florida Developmental Disabilities Council, in 2017 there were an estimated 472,644 people with intellectual developmental disabilities (IDD) in the state of Florida, 75% (352,726) of whom live with a family caregiver. Of the estimated 352,726 family caregivers, 32% (110,955) were over the age of 60 years.

A recent online survey conducted for the FDDC of families providing care for persons with developmental disabilities confirms there is a growing number of aging caregivers with a third over 60. In FY 2017, only 6% (19,463) of the 352,726 family caregivers who had a person with IDD living in their home, received services from the Florida Agency for Persons with Disabilities. The number of these families receiving supports dropped 2.6% between FYs 2016 - 2017. As of February 2021, there were 27,000 individuals on a waitlist for IDD services. The average wait on the waiting list is reported to be 7 years.

The wait lists for persons with developmental disabilities and for persons who are aged and in need of long term care services are a reflection of Florida's underfunding of human services. There are over 65,000 on the Medicaid home and community based services wait list for the aging with disabilities and another 50,000 are waiting for state general revenue funded Community Care for the Elderly services. It is one of only 12 states that has not expanded Medicaid for its citizens without insurance. Most startling, Florida ranks 50th in its funding of long term care for the aging population with disabilities and 49th for services to persons with developmental disabilities. The Governor approved \$95 million this year for DD services but if the DD network is unable to shore up the work force, there is a fear of a return to institutionalization to serve the growing population in need.

Margaret Lynn Duggar then summarized the difficulties facing the Aging & Adult Services network in Florida noting that it is not well coordinated and the

fragmentation of the services and the service delivery means geographic differences and uneven access to care. There have been major changes in the Florida aging services network over the past decade with the managed care takeover of Medicaid nursing home and home/community based services. The state of Florida is divided into 11 geographic areas. Each has an Area Agency on Aging, which operates as the Aging and Disability Resource Center, and is the first point of contact. The process begins when a client calls the Elder Helpline at 1- 800-963-5337 to request an assessment. The client will be called back by a counselor, up to three times. If the client does not answer, a letter is sent but no other follow up.

During the phone assessment, the client, or their caregiver, are not instructed on what the questions mean or how the questions are ranked or scored for the total score for service eligibility. The Florida Department of Elder Affairs Form 701S, Screening Form, is a six page assessment and is used to determine if the person could be Medicaid eligible based on income and assets. This is important information for if the person is potentially eligible for Medicaid and if the application is not submitted, they are not considered for any other services such as Community Care for the Elderly (CCE) or Home Care for the Elderly (HCE) funded services.

The phone assessments are completed annually as long as the client remains on the waiting list. If there is no response, after three attempts, the client is taken off of all waiting lists. The lack of an in-person option is a problem because the person on the phone may not understand the questions being asked or they may overestimate their ability to complete tasks, leading to an incorrect score/assessment. Furthermore, some clients may not have phones or computer access.

The screening assessment does not give any weight to the person (caregiver in this case) having memory loss or dementia nor whether the person (caregiver or the person with developmental disabilities) was in a group home or a nursing home in the last year. The question “Do you need assistance for food?” is also not included in the scoring, but the nutritional screen is to be completed for persons who respond “yes.” The problem is that a person with full dementia or an inability to take care of themselves and living alone in the community with no food, could be assigned a low level of “2” if they respond to all of the questions related to skills in 4 such a way as not needing much help. The phone assessor may not be able to realize the problems.

The completed screening form is submitted to the Department of Elder Affairs Client Information and Registration Tracking System (CIRTS). Individuals are advised to apply for Medicaid if the screening finds they meet the income and

assets' levels. The Comprehensive Assessment and Review for Long Term Care Services (CARES) is assigned the individuals who may meet the level of care for nursing home placement. Choice Counselors are available by phone or face to face appointment for sign up with a managed care provider after the person becomes Medicaid eligible, they meet the nursing home level of care or a slot for home and community based services becomes available and the person is at the top of the wait list for services. It is possible for a person to move to the top of the wait list if a referral is made from Adult Protective Services but the services are intended for an emergency and not for ongoing provision.

A person who is eligible for Medicaid may not be served with General Revenue services through Community Care for the Elderly or Home Care for the Elderly, state funded programs established by Governor Bob Graham almost 40 years ago. The federal Older Americans Act funding is an invaluable resource for congregate care and senior center services, especially in rural communities.

There are now two systems with managed care over one and the Aging Network over the other. The screening intake is by phone and therefore limited. It can be confusing to the caregiver and the client looking for services. AARP recently ranked Florida 51st in the nation for its aging and long term care system due to the state's large waitlist.

Margaret Lynn Duggar encouraged an open discussion for participants and Jean Sherman asked if the emphasis has changed over the past decades in the population served by the aging network. Margaret Lynn Duggar responded that a smaller percentage of need is being served and the wait lists are continuing to grow as the two parallel systems of Managed Care and the Aging Network divide the population served or assigned to the wait list. Jeb Bush was the last governor to fund services for persons specifically on the aging services wait list, over 15 years ago. The wait lists have continued to grow as the boomer population ages and funding has not kept up with the increasing needs.

An overview of the Aging Caregiver Survey that was distributed as part of this initiative was provided to the Summit participants. Demographic data for the 5 participating caregivers includes age groupings for the caregivers and the persons being cared for. A majority of caregiver respondents (51.9%) are between the ages of 60 and 70 with another 27% over 70. A reported 60% of care recipients are under 40, with most between 20 and 39. Of the 309 respondents only 1 was a Spanish speaking response indicating the channels of distribution were insufficient to reach larger numbers of Spanish speakers.

Duval county led the counties with 7.5% of respondents, followed by Broward, Orange, Hillsborough, Marion, Pinellas, Brevard, Palm Beach and Polk.

MiamiDade rounded out the top 10 but with only 14 respondents out of 309 which is low. Miami-Dade has almost one third of Florida's 180,000+ SSI recipients that includes aged as well as blind and persons with disabilities. The rural counties had limited representation with 24 rural counties missing.

Summit Participants React to Survey of Caregivers Report

Jean Sherman initiated the caregivers' survey discussion with a proposal that there be an assessment of the differences by age group on what is needed in the future. Liz Perkins recommended more focus on the Spanish speaking clients for there is a large Hispanic population in Florida. She recommended Spanish speaking persons be invited to the remaining two Summits. Margaret Lynn Duggar asked if the group thought the formation of Spanish speaking focus groups would be helpful. Another possibility would be to reach out to the 206 survey respondents who provided their contact information for possible follow up.

Larry Dixon said that regardless of ethnicity there are common threads in what people are going to need in the near future, especially in regards to assistive housing. He asked the group if a community campus setting would be a solution in a larger institutional setting as opposed to the smaller group homes that are now available, possibly like an ALF with personal assistance available. There are some college campuses that have built continuums of care for persons who are aging. The question is whether or not this a possibility for persons with developmental disabilities? Margaret Lynn Duggar spoke of a model in North Central Florida with HUD housing money available for the ALF setting for the aging parent with an older child with developmental disabilities. One of the findings of the research has been that the adult child becomes even more important in assisting their caregiver who may be aging with basic tasks such as carrying groceries and lifting heavy items in day to day living.

Susan Byram, Co-Founder and Past President of Autism Pensacola, noted that many parents do feel hopeless and it is important to learn what models have been successful. She described a Nashville, Tennessee program where college students live with individuals with developmental disabilities.

The staff at Margaret Lynn Duggar researched the program mentioned and found the following information. Our Place Nashville partners with non-profit organizations to provide brick-and-mortar housing called Friendship Houses throughout the city for adults with developmental disabilities. Our Place Nashville's Divinity Friendship Houses at Vanderbilt create an interdependent living environment comprised of residents with intellectual and/or developmental disabilities ("friends") and graduate students from Vanderbilt

University, primarily from the Divinity School. A third Friendship House was opened in 2019 which integrates young adults with IDD, Vanderbilt Divinity School students and older adults into the Friendship House community. For more information, please visit their website at <https://www.ourplacenashville.org>.

In addition, Vanderbilt University has a program called Next Steps at Vanderbilt. It is a 4-year inclusive higher education program committed to providing students with intellectual disability an inclusive, transformational postsecondary education in academics, social and career development, and independent living, while honoring equality, compassion, and excellence in all endeavors. For more information, please visit their website at <https://peabody.vanderbilt.edu/departments/nextsteps/>.

Summit attendees recommended following up with the survey participants who provided their contact information. The survey summary report was sent to survey respondents following the Summit.

In addition, the Advisory Committee recommended following up with the family caregivers who participated in the Summit to request their feedback and their responses included the following:

“The survey outcome information is brutal when you think about how many people need help and yet are on the waiting list.”

“The communication between organizations is a major problem.”

“Transportation for my daughter is my Achilles heel.”

“Older caregivers need peace of mind that their DD loved ones will be taken care of when the caregivers are no longer here. I would like to see the Aging and DD Networks to consider building affordable housings/communities throughout Florida, similar in concept to Noah’s Ark of Central Florida. I believe Larry Dixon spoke about this. This is urgently needed, as many caregivers are in their 70’s and 80’s!”

“Definitely funding is needed, and I understand that money is always short. We need to work on raising public awareness to this need. Perhaps we can capture the hearts of big donors——much like Tim Tebow, who sponsors proms for the DD population every year.”

“The ideal situation would be a campus like Larry Dixon described with an assisted living type program, where they could have bus rides, work there in the cafeteria, have access to jobs, someone could help with the cleaning and provide any assistance that may be needed. It would be a way for them to live independently and would possibly have different levels of competency there. As an aging parent, it is a difficult thing.”

One participant mentioned a program in Phoenix, Arizona that she had heard about. Upon further research, we found “First Place Phoenix” in Arizona which offers supportive housing for adults with autism, Down syndrome and other neurodiversities and a residential transition program for adults with autism. Their website is <https://www.firstplaceaz.org>.

Programs like Our Place Nashville and First Place Phoenix target individuals who are somewhat independent so alternative options may need to be explored for other individuals.

It is also important for schools with programs for social work, early childhood education, nursing, medical schools, behavioral therapy programs, etc. to provide hands on learning opportunities with individuals with DD.

Valerie Breen asked Margaret Lynn Duggar to follow up on the referenced projects from over 30 years to see what has happened to them. It was recommended that the important question be asked at the forthcoming Summits: Are there ALFs for persons with Developmental Disabilities?

The Summit participants talked about the struggles with daily routines that aging caregivers have with their loved one, such as “Did you brush your teeth today?” One of the components of care management is the educating of the caregiver at times but all of the duties and aspects of case management are not the same for all. Participants agreed there were different forms of case management that were needed based on the families and the level of needs of the persons with developmental disabilities. The highly experienced caregivers participating in the first Summit were very supportive of the services provided but indicated the concern is about when they were no longer going to be able to provide the primary care for their loved ones.

The inability of family members to visit ALFs since Covid19 has lasted 15 months. This has been very concerning. Aging Services expert, Andrea Busada, advised that no matter where their loved one is, the family or friend who is the caregiver has to always remain on top of their care. Nancy Titcher reported a case where a person in an ALF was asked to leave because they were complaining too much. The options are already limited so it is unknown where the person is at this time. Nancy Titcher reported that her local council had looked at ALFs in the surrounding communities and found that none are interested in developmental disabilities.

A discussion ensued over the difficulty in maintaining care workers of persons with developmental disabilities when they are only paid \$8.50 an hour. The CNA in a nursing home may get \$22/hour. Nancy Titcher said the same concern is happening with the Day Programs for developmental services where turn over is common due to the low wages. Another Summit participant, Ella Warren, has a 53 year old daughter with developmental

disabilities who depends on transportation to take her to the day program. But the transportation has been erratic. Andrea Busada suggested that Ella Warren call the Commission for Transportation Disadvantaged to see what could be done for her daughter to get to school.

Margaret Lynn Duggar asked Andrea Busada to describe how Broward County in 1996, when Edith Lederberg was the AAA Director and Nan Rich was an active aging Legislator, provided a \$698,000 line item in the state budget to support the need for services for those on wait lists. The funding has continued for direct services and not administration. Andrea Busada reported that the funding is used to provide support for 127 clients. Hillsborough County is the only other county that funds local service needs.

Liz Perkins expressed feelings of optimism for the goal of the two groups, Aging and Developmental Disabilities, to work more closely together. It will be a challenge to get Floridians to see the hidden communities of people on wait lists and in need of services. We will have to make an investment in people such as increasing the wages of frontline staff.

Margaret Lynn Duggar responded that this work now is the preplanning for the development of the Five Year Plan for the DD Council to identify barriers and resources. One of the areas of concern raised by Summit participants has been the client assessment. Since CIRTS is being redone, it would be a good time to have a discussion with DOEA Secretary Richard Prudom about DD caregiver questions being added to the assessment.

Valerie Breen thanked each of the participants for their involvement in today's Summit and for the preparation for the discussion. She noted there will never be enough services but there is an opportunity for incredible attention being placed on the needs of aging caregivers and their adult children.

The Summit adjourned at 4:08 pm with no break.

Proceedings submitted by: LuMarie Polivka-West

Appendix E

Aging Caregivers' Summit II



Aging Caregivers Summit

Tuesday, June 29th ~ 2:00 PM – 5:00 PM ET

To join using Zoom:

<https://zoom.us/j/94655204708?pwd=NGxQTzIwNUh5cTNuVk0dkd2dTUyUT09>

Meeting ID: 993 6484 5561~ Passcode: 436284

Dial by your location: 646-558-8656 US (New York)

The main purpose is for invited participants, representing both developmentally disabled and aging leaders, to help us identify the most important issues and services persons with developmental disabilities and their family caregivers need as they advance into their 60's and on into old age.

Agenda

2:00 PM Sherman	Welcome & Comments	Valerie Breen/Jean
2:10 PM	Brief Introductions	Everyone
2:30 PM Duggar	Aging Network Summary	Margaret Lynn
2:45 PM	DD Network Summary	Valerie Breen
3:00 PM	Aging Caregiver Survey Summary	Christina DeMeo
3:20 PM	Reactions to the Survey Responses	Everyone
3:45 PM	Break	
4:00 PM	Discussion of Caregiver Survey Responses, Aging & DD Networks & Available Services	Everyone
4:55 PM Breen/Margaret Lynn Duggar	Closing Comments	Valerie
5:00 PM	Adjourn	

Summit Materials can be viewed at:

https://drive.google.com/drive/folders/1SxRLs6Mxm_NZGV8esDcWVM0iqVh_e5HZ?usp=sharing

This Summit is being recorded.

**Aging Caregiver Summit Participants
June 29th, 2021**

Summit Invitees

1. Kristy Carter
Florida Association of Senior Centers
Tallahassee, FL
2. Ryan Chandler, President, Support Coordinator
Chandler Support Services, Inc.
Jacksonville, FL
3. Lynne Daw, Regional Operations Manager
Florida Agency for Persons with Disabilities
Tallahassee, FL
4. Marda Delgado
The WOW Center
Miami, Florida
5. Lori Fahey
Family Café
Tallahassee, FL
6. Lisa Gostel
The WOW Center
Miami, Florida
7. Alesia Macklin
Senior Volunteer Programs Director,
Council on Aging of West Florida, Inc President, Florida Senior Corps
Association (FSCA) Southeast Region Correspondent, AmeriCorps Seniors
Professional Network (ASPN)
Pensacola, FL
8. Janice G. Phillips, Director
HMS / Association for Support Coordination Agencies
Tallahassee, FL
9. Reginald Wheeler
The WOW Center
Miami, Florida

Advisory Committee Members

10. Andrea V. Busada, Director
Broward County Elderly and Veterans Services Division
Oakland Park, FL
11. Larry Dixon
Orange Park, FL
12. Kristen Griffis, Executive Director
Elder Options President of Florida Association of Area Agencies on Aging
Gainesville, FL
13. Lou Ogburn
Tallahassee, FL
14. LuMarie Polivka-West, Sr. Research Associate
The Claude Pepper Foundation
Tallahassee, FL
15. Jean Sherman, Ed.D., RN
Research Assoc. Professor
University of Miami
Pembroke Pines, FL

FDDC:

16. Valerie Breen, Executive Director
Florida Developmental Disabilities Council, Inc. (FDDC)
Tallahassee, FL

Management Firm:

17. Margaret Lynn Duggar, President
Margaret Lynn Duggar & Associates
Tallahassee, FL
18. Christina DeMeo, Program Specialist
Margaret Lynn Duggar & Associates
Tallahassee, FL

Aging Caregivers Summit II Proceedings Summary

Tuesday, June 29, 2021 2:00 pm EST

“The main purpose is for invited participants, representing both developmentally and aging leaders, to help us identify the most important issues and services persons with developmental disabilities and their family caregivers need as they advance into their 60’s and on into old age.”

The Second Aging Caregivers Summit began at 2:03 p.m. with welcoming remarks by Valerie Breen, Executive Director of the Florida Developmental Disabilities Council, Inc. established by the federal government in every state to leverage federal funds and provide advocacy at the local levels. The Council receives \$4 million annually and facilitates advocacy with all partners, including the Legislature and executive branches. The aging caregivers of persons with developmental disabilities has been identified as one of the top five concerns in Florida. This growing concern led to the contract with Margaret Lynn Duggar and Associates for an aging caregivers’ initiative including workgroups and three Summits to strategize together how to address identified needs.

The work of this aging caregivers’ initiative is to provide a road map for the launching of a five year plan this fall. The input of caregivers, policy makers and advocates will be very important to the plan development and implementation. This is the second of three Summits. The first Summit in mid June began with a focus on aging caregivers. We have invited participants from the private and public sectors involved in care management and services for the second Summit today. We also have six members of our advisory committee for this initiative on the Summit today including Dr. Jean Sherman, who along with Dr. Liz Perkins at the University of South Florida, represents a center of excellence at the University of Miami.

Dr. Sherman serves as chair of the state plan policy development for the Florida DD Council and acknowledged that the problems for the aging caregivers is a national problem and the time has come for the public and private sectors to better understand the issues. She recommended that participants look at the wide variety of resources and research provided as a part of this grant’s work.

Each of the fifteen participants were asked to introduce themselves. The Summit participants included a range of affiliations from an Area Agency on Aging, Senior Center and other aging services linked representatives, to support coordinators and 2 managers and Medicaid waiver providers for the DD network and policy/research experts in the related fields. The participants also included six aging caregivers of adult children over 46 years of age with Developmental Disabilities.

The attendees' names and affiliation are:

Valerie Breen, Executive Director, Florida Developmental Disabilities Council, Inc. (FDDC)

Andrea V. Busada, Director, Broward County Elderly and Veterans Services Division

Kristy Carter, Florida Association of Senior Centers

Ryan Chandler, President, Support Coordinator, Chandler Support Services, Inc.

Lynne Daw, Regional Operations Manager, Florida Agency for Persons with Disabilities

Marda Delgado, The WOW Center

Larry Dixon

Lori Fahey, Family Café

Lisa Gostel, The WOW Center

Kristen Griffiths, Executive Director, Elder Options and President of Florida Association of Area Agencies on Aging

Joe McCann, Family Café

Lou Ogburn

Janice G. Phillips, Director, HMS / Association for Support Coordination Agencies

LuMarie Polivka-West, Sr. Research Associate, The Claude Pepper Foundation

Jean Sherman, Ed.D., RN, Research Assoc. Professor, University of Miami

Valerie Breen, a clinical social worker with a forty year history in the field, stressed the need to build a network in Florida for Developmental Disability Services and Aging Services. According to the Florida Developmental Disabilities Council, in 2017 there were an estimated 472,644 people with intellectual developmental disabilities (IDD) in the state of Florida, 75% (352,726) of whom 3 live with a family caregiver. Of the estimated 352,726 family caregivers, 32% (110,955) were over the age of 60 years. These demographics influenced this "Aging Caregivers Initiative" and the work being facilitated by Margaret Lynn Duggar.

Margaret Lynn Duggar has almost 50 years of service in the field of aging beginning as the panhandle Area Agency on Aging Director, and serving as a previous Secretary of Elder Affairs under two governors highlighted the importance of people working together in the aging and the DD networks. She provided a brief overview of the Aging Services in Florida and referred participants to the papers in the packet for more information. The Community Care for the Elderly and Home Care for the Elderly programs are general revenue funded and very popular across the state but there are wait lists for both.

Christina DeMeo, with Margaret Lynn Duggar & Associates, presented an overview of how the Aging Caregiver Survey was distributed for the Florida Developmental Disabilities Council by RB Oppenheim Associates between March 8 and April 15, 2021. The survey intent was to collect caregiver and recipient statewide information on those with intellectual and developmental disabilities. The online survey was sent via email, advertised on social media (Facebook, Twitter and LinkedIn) and the Florida Council on Aging also sent the survey out by email to almost 8000 recipients. An average of 20% of recipients opened the emails sent by RB Oppenheim Associates with 309 responses received for a reported 36.9% completion rate from the opened views. Older parents of an adult child with developmental disabilities represented 85.4% of the respondents.

A majority of caregiver respondents (51.9%) are between the ages of 60 and 70 with another 27% over 70. A reported 60% of care recipients are under 40, with most between 20 and 39. Of the 309 respondents only 1 was a Spanish speaking response indicating the channels of distribution were insufficient to reach larger numbers of Spanish speakers.

Duval county led the counties with 7.5% of respondents, followed by Broward, Orange, Hillsborough, Marion, Pinellas, Brevard, Palm Beach and Polk. MiamiDade rounded out the top 10 but with only 14 respondents out of 309 which is low. Miami-Dade has almost one third of Florida's 180,000+ SSI recipients that includes aged as well as blind and persons with disabilities.

Approximately 51% of the responding caregivers receive services and 68.6% of the care receivers. The major reported service for both the caregiver and the 4 recipient is case management for around 80% of those receiving services. Approximately 30% of the aging caregivers care for an adult child with autism. There were significant differences between care reported as received now and what is anticipated for the future. For example, the need for home delivered meals is anticipated to increase in the future although it is not a very common service now for adult caregivers with an adult child with developmental disabilities. Another indicator of need are waiting lists and 14% of the responding aging caregivers said they are on a DD wait list and 10% reported being on a wait list for aging services. A majority of respondents said that they need more services with less bureaucracy.

Janice Phillips recommended the survey report as helpful for agencies both for aging services and developmental disabilities to inform others how people are having to choose between agencies even though they have needs for both. People want to stay in their own homes as long as possible but there is a need to plan for change.

Valerie Breen noted that the survey results indicated case management is critical as a person begins services but that respondents felt more varied services are needed than case management. Larry Dixon suggested that age subsets be looked at such as 60 and older rather than 21+ for the analysis of services provided and anticipated in the future.

Margaret Lynn Duggar then summarized the difficulties facing the Aging & Adult Services network in Florida; noting that it is not well coordinated and the fragmentation

of the services and the service delivery means geographic differences and uneven access to care. Jean Sherman responded that it is not so different in the DD network where all services are not available in all regions so there is a geographic imbalance of services.

Margaret Lynn Duggar further suggested that the intent is to try and put together two unwieldy systems. Participants were directed to the two papers that are in the packet that describe the Aging Services and the DD systems in Florida. Both have long wait lists for services with the Medicaid waiver for home and community based services as well as for general revenue funded programs.

Janice Phillips expressed concern that some DD care workers are concerned about doing anything for an aging parent when in the home providing services for an adult with disabilities. Transportation is a difficult service for an assistant might be needed but unavailable.

Andrea Busada, Director of the Broward County Elderly and Veterans Services Division, proposed these concerns be training topics for APD and CCE care managers to be trained together in certain geographic areas. Broward County provides case management but contracts out the other services. Other areas have the CCE lead agency provide all of the services. Valerie Breen responded that Barbara Palmer, APD Director, is very supportive of joint training across the aging services and the DD networks. There have been such projects in the past in some areas.

Valerie Breen related that Alison Barkoff, the ACL (Administration for Community Living) Acting Administrator and Assistant Secretary for Aging, has led policy advocacy with federal agencies and Congress and legal advocacy nationally to advance community living and inclusion, including in the areas of healthcare, Medicaid home- and community-based services, employment, housing, and education. Alison Barkoff also has an older brother who has developmental disabilities which gives her much personal experience as well as a lengthy career in the field of developmental services. We think Florida will be in the lens of how aging and developmental services will plan to work together for aging caregivers with aging children with developmental disabilities.

Lou Ogburn emphasized the need to come up with a range of options for congregate living for aging caregivers and their adult children with DD along the lines that the aging population has in many communities with independent living, assisted living and services brought into the home. There are more congregate type housing options in the more populated parts of the state.

Janice Phillips shared the success of planning the development for Independence Landing in Tallahassee over the past three years. Soon the ground will be broken and the building will commence. The hope is that the progress with Independence Landing will be a model for other communities. Valerie Breen agreed that one of the major concerns is finding residential living options for caregivers that provide necessary services but also provide oversight and safety. The independent living setting has limited services of maybe some meals and transportation. But other services may be needed while trying to maintain the

least restrictive settings. There are liability concerns with planned communities but all of this needs to be reviewed.

The participants discussed their concerns about a living wage for the service workers in aging and in the DD networks. The staffing agencies that provide CNAs for work charge \$20 to \$22 an hour but the CNA gets less than 2/3rd of that. Even so many of the community providers are not prepared to pay those rates. Living wages were identified as a shared critical concern in order to reduce turnover.

Jean Sherman recommended that the Agency for Health Care Administration be brought in for the cross training proposals given their role with the Medicaid waiver program and oversight of the waivers. Cross training is needed for identifying how the different networks provide services to the same people in need and who is wait listed for services. Training is recommended for “how things fit or not” and how to maximize services. Kristy Carter, experienced in Senior Center programs and recreational activities, emphasized that people need to feel welcomed in their respective environments and they need to be encouraged to be their own advocate.

Margaret Lynn Duggar encouraged participants to share their own stories and the stories of others, to be a model for the rest of the nation in how the needs for aging caregivers are identified and addressed in the next five year state plan. Larry Dixon shared his past experiences of working in both the aging and the DD networks of how he successfully transitioned some of his aging clients into the Aging Network from the DD network. It was a natural transition at the Senior Center and is a model for others.

The meeting adjourned at 3:55 p.m.

Proceedings by LuMarie Polivka-West, July 5, 2021.

Appendix F

Aging Caregivers' Summit III



Aging Caregivers Summit

Friday, August 27, 2021 ~ 3:30 PM – 5:30 PM ET

To join using Zoom:

<https://zoom.us/j/94655204708?pwd=NGxQTzIwNUh5cTNuVk0dkd2dTUyUT09>

Meeting ID: 995 8892 9288 ~ Passcode: 675290

Dial by your location: 646-558-8656 US (New York)

The main purpose is for invited participants, representing both developmentally disabled and aging leaders, to help us identify the most important issues and services persons with developmental disabilities and their family caregivers need as they advance into their 60's and on into old age.

3:30 PM	Welcome & Comments	Valerie Breen, Executive Director
3:40 PM <i>Facilitator</i>	Brief Introductions	Everyone/Margaret Lynn Duggar,
3:50 PM <i>Jones</i>	Aging Perspectives from ACL	Constantinos "Costas" Miskis/David
4:10 PM <i>Jones</i>	DD Perspectives from ACL	Constantinos "Costas" Miskis/David
4:20 PM	Perspectives from State Agencies	Director Barbara Palmer <i>Agency for Persons with Disabilities</i> Secretary Simone Marstiller <i>Agency for Health Care Administration</i> Secretary Richard Prudom <i>Department of Elder Affairs</i>
4:30 PM <i>Facilitator</i>	Dialogue & Discussion of Questions	Everyone/Margaret Lynn Duggar,
5:25 PM	Closing Comments	Valerie Breen/Margaret Lynn Duggar
5:30 PM	Adjourn	

Summit Materials can be viewed at:

https://drive.google.com/drive/folders/1SxRLs6Mxm_NZGV8esDcWVM0iqVh_e5HZ?usp=sharing

This Summit is being recorded.

Aging Caregiver Summit Participants

August 27th, 2021

Summit Invitees

Administration for Community Living

1. David Jones, Director
Office of Intellectual and Developmental Disabilities (OIDD) and Acting
Director, Office of Disability Services Innovation (ODSI) Administration for
Community Living U.S. Department of Health and Human Services
2. Constantinos “Costas” Miskis, Regional Administrator,
Region IV Administration for Community Living U.S. Department of Health
and Human Services
Atlanta, GA

State Agencies

3. Simone Marstiller, Secretary
Agency for Health Care Administration
Tallahassee, FL
4. Barbara Palmer, Director
Agency for Persons with Disabilities
Tallahassee, FL
5. Richard Prudom, Secretary
Department of Elder Affairs
Tallahassee, FL

Legislative Staff

6. Eric Lloyd
Policy Chief for the Finance and Facilities Subcommittee in the House Health
and Human Services Committee
Tallahassee, FL

Advisory Committee Members

7. Jessica Ayers MS, BSW,
The Retreat Director Council on Aging of West Florida, Inc.
Pensacola, FL
8. Andrea V. Busada, Director
Broward County Elderly and Veterans Services Division
Oakland Park, FL

9. Larry Dixon
Orange Park, FL
10. Kristen Griffis, Executive Director
Elder Options President of Florida Association of Area Agencies on Aging
Gainesville, FL
11. Lou Ogburn
Tallahassee, FL
12. Elizabeth A. Perkins, PhD, RNLD, FAAIDD, FGSA
Associate Director and Research Associate Professor
Florida Center for Inclusive Communities/UCEDD Department of Child and
Family Studies College of Behavioral and Community Sciences
University of South Florida
Tampa, FL
13. LuMarie Polivka-West, Sr. Research Associate
The Claude Pepper Foundation
Tallahassee, FL
14. Jean Sherman, Ed.D., RN
Research Assoc. Professor
University of Miami
Pembroke Pines, FL

FDDC:

15. Valerie Breen, Executive Director
Florida Developmental Disabilities Council, Inc. (FDDC)
Tallahassee, FL
16. Margaret J. Hooper, Director of Public Policy and Advocacy
Florida Developmental Disabilities Council, Inc. (FDDC)
Tallahassee, FL

Management Firm:

17. Margaret Lynn Duggar, President
Margaret Lynn Duggar & Associates
Tallahassee, FL
18. Christina DeMeo, Program Specialist
Margaret Lynn Duggar & Associates
Tallahassee, FL

Aging Caregivers' Summit III Proceedings Summary

Friday, August 27, 2021 3:30 pm EST

The Third Aging Caregivers Summit began with welcoming remarks by Valerie Breen, Executive Director of the Florida Developmental Disabilities Council, Inc. established in 1971 for building resources and facilitating change for improving services for persons with developmental disabilities. The aging caregivers of persons with developmental disabilities have been identified as one of the top five concerns in Florida. This growing concern led to the contract with Margaret Lynn Duggar and Associates for an aging caregivers' initiative including workgroups and three Summits to strategize together how to address identified needs.

Valerie Breen welcomed the Summit participants representing the Administration for Community Living (ACL) in Washington, D. C. and Atlanta, Georgia's Region IV office and the state agency leaders. Their input was recognized as very important for the work of this aging caregivers' initiative to provide a road map for the launching of a five year plan this fall. The input of national and state leaders, caregivers, policy makers and advocates are integral to the plan development and implementation. This is the third and final Summit. The first Summit in mid June began with a focus on aging caregivers; followed by a second Summit with participants from the private and public sectors providing care management for persons with developmental disabilities and aging service providers. The Advisory Committee for the initiative has been instrumental in the work progress to date.

The Summit III included two representatives from the federal Administration for Community Living, Costas Miskis and David Jones. David Jones, Director of the Office of Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services worked in two federal agencies focused on disability employment and programs prior to moving to ACL in July 2020. Costas Miskis, ACL Regional Administrator with Region IV, worked as legal counsel for the Florida Agency for Health Care Administration and the Department of Elder Affairs prior to joining the Region IV Department of Health and Human Services (DHHS).

Covid19 and the American Rescue Plan

Their discussion began with the federal focus on Covid19 and recognition of the terrible impact on seniors with one third of the Covid19 deaths in U.S. nursing homes. Nursing home residents represented only 4% of the Covid19 cases but 31% of the Covid19 deaths. The need for continued vaccination of nursing home residents and the nursing home employees is being focused on at the DHHS.

Covid19 related relief is a part of the American Rescue Plan signed into law in March 2021, the fifth COVID-19 relief package, totaling \$1.9 trillion. The law provides to states \$360 billion in aid with a number of additional provisions to improve access to health

care and increase economic security for older adults during the pandemic. The stimulus payments included in this plan do not affect eligibility for Medicaid, SSI or SNAP (food stamps). The American Rescue Plan also distributed \$65 billion directly to counties based on population. Florida's Agency for Health Care Administration submitted a plan for the Medicaid related funding opportunities in July 2021 for distribution of the American Rescue Plan funds across the state agencies of Medicaid, Elder Affairs and the Agency for Developmental Services.

Important funding areas for aging caregivers of persons with disabilities include the following:

- **Housing Assistance.** The law includes increased funding for emergency rental assistance, with targeted distributions to high-need communities (\$27.4 billion); funding for housing vouchers (\$5 billion); tribal and rural assistance (\$850 million); homelessness assistance (\$5 billion); and homeowner assistance to prevent foreclosure (\$10 billion).

My adult son needs a residential community with supported living services for growth and social engagement and integration into a community. We are very isolated in my old age.

- **Utility Assistance.** The law includes \$4.5 billion to provide energy assistance through the Low-Income Home Energy Assistance Program (LIHEAP) and \$500 million for water assistance through the Low Income Household Drinking Water & Wastewater Emergency Assistance Program,
- **Food Assistance.** The law extends the 15% increase in SNAP benefits through September 30, 2021, funds grants to Puerto Rico, the Commonwealth of the Northern Mariana Islands, and American Samoa (\$1 billion), and provides additional SNAP administrative funds to states to help meet increased caseload demand (\$1.1 billion). It also includes \$37 million in funding for the Commodity Supplemental Food Program for the improvement of the health and nutrition of 3 low-income individuals over 60 years old and \$750 million for nutrition programs under the Older Americans Act.
- **Medicaid Home and Community Based Services (HCBS).** The law includes a 10% increase in federal Medicaid funding to states totaling \$12.7 billion specifically for home and community-based services (HCBS), including behavioral health. States must use the increased funding to supplement, not supplant, HCBS programs and services in effect as of April 1, 2021. The increased funding will apply to eligible HCBS spending through March, 2022.
- **Nursing Homes.** The law includes funding for states to create strike teams for resident and employee safety in nursing facilities (\$250 million) and funding for Health and Human Services to develop and disseminate protocols to prevent or mitigate COVID-19 in skilled nursing facilities (\$200 million).
- **Increased Vaccination Funding.** The law enhances funding for vaccination efforts, including targeted funding to reach communities of color, tribes, rural areas, and other

underserved communities for establishing vaccine sites across the country and deploying mobile vaccination units.

- **Other Medicaid Funding.** The law also requires states to cover COVID-19 testing, treatment, vaccines, and vaccine administration for uninsured individuals, including immigrants eligible for emergency Medicaid, and includes 100% federal funding for this coverage. In addition, the law increases federal funding for Medicaid mobile crisis intervention teams to 85%.

- **Medicaid Expansion Incentive** (Florida is one of the 12 states that has not expanded Medicaid). The law provides any state that decides to expand Medicaid an additional 5% increase in federal funding for two years for older adults and other populations states are already required to cover. This is in addition to the 90% federal funding for the expansion population authorized under the Affordable Care Act. The law expands and increases premium assistance for individuals purchasing health insurance on the marketplace for the next two years. Under the law, no one will have to pay more than 8.5% of their income on the marketplace. This change helps older adults under age 65 with moderate incomes who pay increased premiums based on age. Additionally, individuals with incomes below 150% of the federal poverty level will pay no premiums and anyone who receives unemployment benefits in 2021 will be able to purchase a silver plan on the marketplace with no premium.

- **Aging and Disability Services.** The law provides \$1.4 billion increased funding for programs under the Older Americans Act including \$750 million for home delivered meals \$460 million for supportive services such as personal care, chore, and including COVID-19 vaccine outreach and coordination and efforts to address social isolation; \$25 million for services for Native American communities; \$44 million for evidence-based health promotion and disease and falls prevention programs; \$145 million for the National Family Caregiver Support Program; and \$10 million for the Long-Term Care Ombudsman Program. The law also includes \$50 million for grants to public transit systems to improve transportation access for older adults and people with disabilities.

- **National Center for Grandfamilies.** The law provides funding to create a new technical assistance center for grandfamilies and kinship families to provide training, technical assistance, and resources to government programs, communitybased organization, and Tribes and Tribal organizations that serve grandfamilies and kinship families in which the primary caregiver is an adult age 55 or older or the child has one or more disabilities.

- **Native American Language Preservation.** The law includes \$20 million for Native American elders to preserve Native American languages that have diminished due to COVID-19.

- **Community Health Centers & Indian Health Service.** The law includes \$7.6 billion in funding for Community Health Centers to respond to COVID-19 and \$.3.5 billion for the Indian Health Service.

- Farmworker Equity.

- The law includes \$5 billion in assistance to support disadvantaged farmers with financial training, property issues, training the next generation of farmers, and with land access. It is estimated that one quarter of disadvantaged farmers are Black. The ACL is committed to improving the lives of older caregivers and for those with developmental disabilities. There has been an 134% increase between 1998 and 2017 in the population with developmental disabilities. Over a million families are impacted and only 1/3 have developed advance care plans.

Florida leaders and advocates were encouraged to communicate frequently with their state legislators about the growing wait lists for both the aging population and for persons with developmental disabilities. =

Florida's Plan for the American Rescue Plan

Secretary Simone Marstiller reported that the Agency for Health Care Administration (AHCA) recently submitted the "Home and Community-based Services Spending Plan and Narrative" to the Department of Health and Human Services. AHCA Secretary Simone Marstiller and the Secretary of the Department of Elder Affairs, Richard Prudom, and the Director of the Agency for Persons with Disabilities, Barbara Palmer, participated in Summit III and discussed the Florida plan for the American Rescue Plan funds. Each of their agencies participated in the plan development and includes the following:

- A one time stipend to all Home and Community-based Service providers for distribution to their workforce. The stipend is proposed for both managed care and fee for service providers to encourage hiring and retention of workers.
- A one time payment to persons 60 and older participating in a public assistance program and reside in a "family type living arrangement in a private home."
- Funds will be made available for the purchase of improved technological supports and technological advancements across the state agencies for the reporting and accountability of programs.
- Funds will be made available for the purchase of equipment such as wheelchair transfer board, eyeglasses, adaptive equipment through the HCBS service networks.
- There will be funds for mental health, substance abuse and behavioral health concerns related to the pandemic.
- A payment increase for Prescribed Pediatric Extended Care (PPEC) providers.

Summit participants supported the home and community based service expansion through Medicaid for persons on the wait list. The APD Director, Barbara Palmer, stressed the need to focus on the family with the aging caregiver and an adult child with developmental disabilities with cross training for staff in the two different fields of service delivery. Jean Sherman, University of Miami professor and caregiver, emphasized

the need for a family assessment that would include the aging caregiver(s) and the adult child with intellectual/developmental disabilities.

The Administration for Community Living was formed as an example of how to bridge the aging and developmental disabilities silos with a promotion of the Aging and Disability Resource Centers in the states. The ACL has targeted grant funding to 10 states for bridging aging and disabilities networks. Many of the states' models are changing from a system focus to the customer with different agencies working together such as DD and Mental Health. Maryland, New Hampshire, and Missouri were highlighted as states with innovative projects that promote state programs working closely together in serving families with the cross training of staff. Secretary Prudom, Department of Elder Affairs, responded that Florida's Agency for Health Care Administration is working on a common client assessment number and information sharing across departments. The state agency leaders are meeting monthly to oversee the interagency work in progress.

Summit participants discussed how a Memorandum of Understanding could facilitate the collaboration and leveraging of the partnerships. One example is the DOEA Meals on Wheels program that serves the family of both an aging caregiver and the adult child. A streamlined bureaucratic process would assess the eligibility and needs of the family rather than the individuals separately for home delivered meals.

Another key area of concern that was posed as a possibility to address rather than as a barrier is the shortage of direct care workers. The American Rescue Plan funding through increased federal Medicaid funds will help providers this year hopefully retain more staff. The special federal funds will enable Florida APD to reach more customers on the wait list.

Richard Prudom acknowledged the ever increasing aging population of Florida where 5 million of 20 million Floridians are over 60. There has been a disproportionate impact from Covid19 on aging Floridians and the state has had to be innovative and more flexible because of the pandemic. Many congregate meals sites were reduced or closed and one successful example is how the DOEA has partnered with restaurants to prepare the increased meals and in some areas to deliver them. This is being carefully looked at because of concerns of increased social isolation with the meals being delivered rather than in a congregate setting. The need is to focus on aging communities and their caregiving responsibilities with economic security, education, transportation and access to mental health services.

Larry Dixon, retired City of Jacksonville Senior Services and former DD support coordinator and family caregiver, shared an example of encouraging clients of DD services to participate in Senior Center activities. Kristen Griffis, CEO of Elder Options, and Andrea Busada, Director of Broward County Elderly and Veterans Services expressed support for the degradation of silos at the local level to allow more of a family approach to care.

Jessica Ayers, The Retreat Director, expressed concern about people being told they make too much when asking for services because the front line people answering the phone have not been appropriately trained. Increased and improved cross agency training was a major recommendation throughout the Summit.

Valerie Breen closed the Summit with a call for breaking down the silos of aging and developmental disabilities for a promotion of access to needed services and supports. The Aging Caregivers Initiative Final Report and the Five Year Plan will be forthcoming.

Appendix G

American Rescue Plan's Funding Areas for Aging Caregivers of
Persons With Disabilities

American Rescue Plan's funding areas for aging caregivers of persons with disabilities include the following:

- **Housing Assistance.** The law includes increased funding for emergency rental assistance, with targeted distributions to high-need communities (\$27.4 billion); funding for housing vouchers (\$5 billion); tribal and rural assistance (\$850 million); homelessness assistance (\$5 billion); and homeowner assistance to prevent foreclosure (\$10 billion).
- **Utility Assistance.** The law includes \$4.5 billion to provide energy assistance through the Low-Income Home Energy Assistance Program (LIHEAP) and \$500 million for water assistance through the Low Income Household Drinking Water & Wastewater Emergency Assistance Program.
- **Food Assistance.** The law extends the 15% increase in SNAP benefits through September 30, 2021, funds grants to Puerto Rico, the Commonwealth of the Northern Mariana Islands, and American Samoa (\$1 billion), and provides additional SNAP administrative funds to states to help meet increased caseload demand (\$1.1 billion). It also includes \$37 million in funding for the Commodity Supplemental Food Program for the improvement of the health and nutrition of low-income individuals over 60 years old and \$750 million for nutrition programs under the Older Americans Act.
- **Medicaid Home and Community Based Services (HCBS).** The law includes a 10% increase in federal Medicaid funding to states totaling \$12.7 billion specifically for home and community-based services (HCBS), including behavioral health. States must use the increased funding to supplement, not supplant, HCBS programs and services in effect as of April 1, 2021. The increased funding will apply to eligible HCBS spending through March, 2022.
- **Nursing Homes.** The law includes funding for states to create strike teams for resident and employee safety in nursing facilities (\$250 million) and funding for Health and Human Services to develop and disseminate protocols to prevent or mitigate COVID-19 in skilled nursing facilities (\$200 million).
- **Increased Vaccination Funding.** The law enhances funding for vaccination efforts, including targeted funding to reach communities of color, tribes, rural areas, and other underserved communities for establishing vaccine sites across the country and deploying mobile vaccination units.
- **Other Medicaid Funding.** The law also requires states to cover COVID-19 testing, treatment, vaccines, and vaccine administration for uninsured individuals, including immigrants eligible for emergency Medicaid, and includes 100% federal funding for this coverage. In addition, the law increases federal funding for Medicaid mobile crisis intervention teams to 85%.
- **Medicaid Expansion Incentive** (Florida is one of the 12 states that has not expanded Medicaid). The law provides any state that decides to expand Medicaid an additional 5% increase in federal funding for two years for older adults and other populations states are

already required to cover. This is in addition to the 90% federal funding for the expansion population authorized under the Affordable Care Act.

The law expands and increases premium assistance for individuals purchasing health insurance on the marketplace for the next two years. Under the law, no one will have to pay more than 8.5% of their income on the marketplace. This change helps older adults under age 65 with moderate incomes who pay increased premiums based on age. Additionally, individuals with incomes below 150% of the federal poverty level will pay no premiums and anyone who receives unemployment benefits in 2021 will be able to purchase a silver plan on the marketplace with no premium.

The law also includes \$50 million for grants to public transit systems to improve transportation access for older adults and people with disabilities.

- National Center for Grandfamilies. The law provides funding to create a new technical assistance center for grandfamilies and kinship families to provide training, technical assistance, and resources to government programs, communitybased organization, and Tribes and Tribal organizations that serve grandfamilies and kinship families in which the primary caregiver is an adult age 55 or older or the child has one or more disabilities.
- Native American Language Preservation. The law includes \$20 million for Native American elders to preserve Native American languages that have diminished due to COVID-19.
- Community Health Centers & Indian Health Service. The law includes \$7.6 billion in funding for Community Health Centers to respond to COVID-19 and \$.3.5 billion for the Indian Health Service.
- Farmworker Equity. The law includes \$5 billion in assistance to support disadvantaged farmers with financial training, property issues, training the next generation of farmers, and with land access. It is estimated that one quarter of disadvantaged farmers are Black.

Appendix H

Review of the Florida Aging Caregivers' Survey

Review of the Florida Aging Caregiver Survey, May 12, 2021

by LuMarie Polivka-West

The Aging Caregiver Survey was distributed for the Florida Developmental Disabilities Council by RB Oppenheim Associates between March 8 and April 15, 2021. The survey intent was to collect caregiver and recipient statewide information on those with intellectual and developmental disabilities. The online survey was sent via email, advertised on social media (Facebook, Twitter and LinkedIn) and the Florida Council on Aging also sent the survey out by email to almost 8000 recipients. An average of 20% of recipients opened the emails sent by RB Oppenheim Associates with 309 responses received for a reported 36.9% completion rate from the opened views. Older parents of an adult child with developmental disabilities represented 85.4% of the respondents.

Demographic Data

Demographic data for the participating caregivers includes age groupings for the caregivers and the persons being cared for. A majority of caregiver respondents (51.9%) are between the ages of 60 and 70 with another 27% over 70. A reported 60% of care recipients are under 40, with most between 20 and 39. Of the 309 respondents only 1 was a Spanish speaking response indicating the channels of distribution were insufficient to reach larger numbers of Spanish speakers.

Duval county led the counties with 7.5% of respondents, followed by Broward, Orange, Hillsborough, Marion, Pinellas, Brevard, Palm Beach and Polk. Miami-Dade rounded out the top 10 but with only 14 respondents out of 309 which is low. Miami-Dade has almost one third of Florida's 180,000+ SSI recipients that includes aged as well as blind and persons with disabilities. The rural counties had limited representation with 24 rural counties missing.

The question could be asked if the 309 sample is a convenience sampling of current caregivers favoring people who get services in the more urban locales with internet access? The demographic profile that emerges is a caregiver who is aging and living in their own home or apartment (99%) with an adult child with intellectual disability or autism (70% for both) while 82% of the care recipients live with their caregiver. A majority of the remaining almost 18% of care recipients live in their own home or apartment followed by a group home or assisted living.

Community-based Services Received

Approximately 51% of the responding caregivers receive services and 68.6% of the care receivers. The major reported service for both the caregiver and the recipient is case management for around 80% of those receiving services. Given the complexity of different programs and eligibility processes as well as a long wait list for community services, care management is a major concern for family caregivers.

“Currently there are no proper services provided for the developmentally disabled, making it necessary for the aging parent to play this role. As an aging parent, this is not sustainable. I am not aware of any provisions made by APD to provide the required comprehensive services needed by aging developmentally individuals.... they are living longer and will outlive their parents. The State is not prepared and is not allocating the necessary funding to create the plan and establish it.” Caregiver comment #39

The survey results on services being received are very similar between the caregiver and the person with the developmental disability. The comments on services received indicate the caregiver may have been responding sometimes to the question on behalf of the care recipient even though the question is asked of the caregiver. For example, “he receives food stamps and SSI support” and “in-home support services/help with chores” may be reported as services received by both the caregiver and the care recipient.

“I have a hard time just taking care of things around the house because of my health and my enjoyment in life is at a major low point because I just cannot be and do everything like I used to be able to do. I remember meeting other older moms, when I was younger, hearing them express that they had gone downhill”

As mentioned earlier, the reporting of services is for the 51.5% of caregivers and 68.6% of care recipients who are reported as receiving a service. It is not possible to determine the service intensity for the care recipients or the caregivers, only the percentage of respondents who receive each service. For example, case management/care coordinator is the most frequent service provided at around 80% and “companion/aide to take the person into the community” ranks second at 31.6% of the care recipients and 25.2% of the caregivers. The close third ranked service is “personal care attendant” and “adult day care” is fourth. Therefore, one may assume that different services are care planned but the case management is more common across services. Transportation is the fifth ranked, followed by respite care, therapies, counseling and nursing.

“I no longer can care patiently. I am not a safe driver, on pain pills for chronic pain. He has not had adult day services since pandemic. I am depressed and overwhelmed. We were on the waiting list for 16 years before we got any help. The so-called services have been inadequate and unreliable. Still feel his total care needs are all on me.....Florida should be ashamed of the way that this dependent population are treated.”

Services Needed in the Future

There are significant differences between the services currently being received and the identification of services that will be needed in the future as both the caregiver and the person receiving care ages. Case management drops to 68.5% while companion/aide anticipated future need doubles from 31% to almost 60%; personal care need rises to 51.6%; transportation from 15% to 51%; respite care from 15% to 47%; adult day care from 27% to 43%; with the following services increasing to 33 – 37%: wellness, therapies, counseling, and personal emergency response.

Even home delivered meals, a service reported for only .9% of persons with developmental disabilities during the time of the survey, are anticipated to grow to 24.4% of recipients of care. Additional service needs were identified in the areas of guardianship, financial management assistance, and needs for different types of housing including supported living in a residential community.

The anticipation of such growth in service needs in the future are reflected also in the comments, such as:

As I get older, how will I pick him up and transfer him? My back is already pinched in 6 vertebrates. How do I keep this up?

Been on APD waitlist for 15 years. He's now an adult. Need waiver program assistance soon.

Fear of me and my husband dying and leaving our autistic adult twins without appropriate housing and care.

There were many comments related to the caregiver dying or becoming disabled and unable to continue caring for the person(s) and not having an alternative caregiver. The caregivers recognize the major role they have in ensuring the care is provided often by themselves with intermittent assistance when services are provided.

The Rosalynn Carter Institute for Caregiving published [survey results](#), October 2020, of primary caregivers where 83% of caregivers reported increased stress related to caregiving since the start of the Covid19 pandemic. Financial concerns and resource insecurity were also reported sources of stress in addition to Covid19 possible infection. Caregivers reported increased burden from added caregiving responsibilities with the reduction in services and also a decline in available informal assistance.

Several of the caregiver respondents in this survey mentioned the impacts of Covid19; primarily concerns with reduced services and lack of available staff to provide needed services. Concerns with being at home all the time with a lack of activities were also mentioned. The concerns identified by the Rosalynn Carter Institute for Caregiving study were comparable for this survey of Florida caregivers. The financial stress of meeting the day to day needs of the care recipient and the financial barriers in planning for the future were raised by many of the caregivers.

According to the University of South Florida report “[About the iBudget DD Waiver and Waitlist](#)” there were 22,718 persons on Florida’s DD waitlist in January 2021. Many have been on the list for ten years or more. Many of the respondents indicated that services provided are limited and there are concerns with the stability of the services with turnover of staff.

“My ability to physically perform daily care for him...I’m 4’11” inches and weigh 83 pounds with severe arthritis. My son is 6 feet, blind, profoundly intellectually impaired and requires assistance with every aspect of his day – feeding, toileting, walking. He is

nonverbal and extremely aggressive when he doesn't understand what is happening and combative towards me for some essential daily care routines.”

The number of persons with intellectual and developmental disabilities on waiting lists to receive Medicaid funded home and community based services is increasing as needs exceed the funding. A majority of the states maintain a DD waiting list. The federal government allows this for the Medicaid funded home and community-based services under the Section 1115 waiver. An important consideration for the caregiver is that institutional care under Medicaid is an entitlement so no wait list is maintained as it is for community based services. A national annual report entitled “[Case for Inclusion 2020](#)” published by the ANCOR Foundation and United Cerebral Palsy (UCP) reported almost half a million people on wait lists in 2017 for community services.

An important consideration, in addition to the need for more funding, is the workforce shortage. The “[Case for Inclusion](#)” report faults the low wages, the national median wage is reported as \$12.09 an hour, as a cause of the high vacancy rates as well as the high turnover in the frontline positions of providing care in the community.

“We have been on a waiting list since they were 3 and they are now 16 and we are still on a very long list. Will we ever get help?”

The “Case for Inclusion 2020” report emphasizes the significant needs that people with disabilities and their caregivers are increasingly facing. “...It is absolutely critical that lawmakers at all levels of government understand how decades of underinvestment in long-term supports and services for people with I/DD has been one of our generation’s most significant public policy failures,” according to Barbara Merrill, CEO for the ANCOR Foundation.

“Who will take care of my child and make sure he is safe and healthy when I am no longer able to? How long will I be able to care for him? It gets physically and mentally exhausting to fight for and justify everything.”

How to Access Services

Respondents were divided in roughly thirds when asked if they know where to access information on future service needs with 37.7% reporting they did not know, another 34% responding “yes” and 28% a “maybe.” Approximately 52% of caregivers said they are not familiar with the local Area Agency on Aging or what it does while 30% said they were familiar and 18% “not sure.”

When asked “Are you on a waiting list for services?” almost 80% said “No” and 14% yes with the remaining 6% “unsure.” The responses present a profile of a third of the

caregivers informed of the local Area Agency on Aging and knowing where to get information on future services but a small minority of the care recipients on the waiting list. The caregivers' acknowledged that 10% of them have applied for services for their adult child that are funded for aging adults but they have not been successful because the adult child is receiving services from the Developmental Disabilities Waiver.

Caregivers' Wishes

When asked "If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?", the vast majority commented on the need for services, for qualified staff, for less bureaucracy in trying to access services with more assuredness of services than year to year.

"Fair wages to attract qualified personal care and supported living staff."

"Better pay for APD's Direct Service Providers so the staff openings can be filled and staff will stay. New staff all the time is not good for a person with ID/DD."

"There are no services or quality help for anyone over 22."

"There is a lack of reliable support personnel. Group homes and day programs for individuals with significant behavioral issues are hard to find."

"Having a residential community with supported living services available for my adult son so that there are multiple opportunities for growth, social engagement and integration into the greater community in a safe enriched environment."

Summary

A majority of the caregivers who responded to the online survey are aging in place in their own homes with their adult child who has intellectual and developmental disabilities who is also aging into their middle ages. Services are limited. The waitlist for community-based services is acknowledged as a process that doesn't move very fast with several caregivers noting the years they have been waiting for services. Problems are

noted with having trained, quality staff who are paid enough to remain in their jobs providing DD services in the community. The continuity of care is viewed as the responsibility of the primary caregiver but there are major concerns about their becoming ill and dying in the future. What will happen to their loved one?

The Advisory Committee for this project raised concerns about the low representation of the rural communities in the survey and proposed that the planned Summits should include participants from rural areas as well as the urban participants. Questions were also raised about the lower percentage of service participants under 30; the low ranking of transportation in the services received (but could be related to the Covid19 closures); and concerns about the DD and aging services' networks working together to promote integrated services while recognizing long wait lists for both populations.

Appendix I

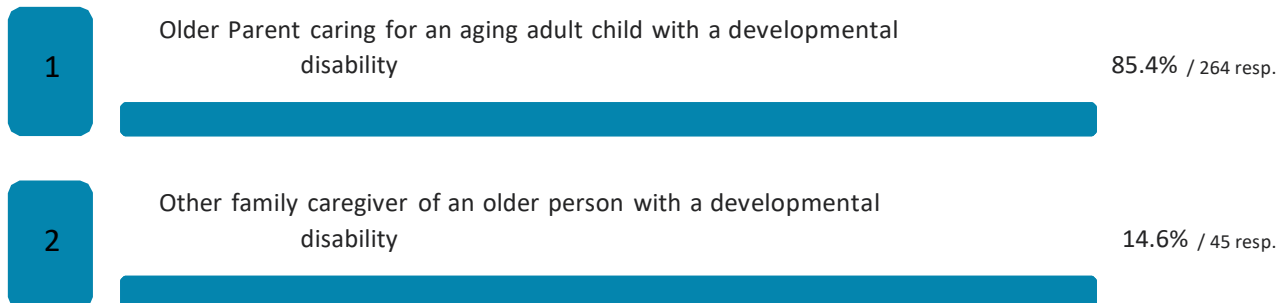
Actual Caregivers' Survey Report With Results

Aging Caregiver Survey - FDDC ACTUAL

308 English responses, 1 Spanish response

Question 1 Select the option that best describes you:

309 out of 309 answered



Reports can be found online at:

English - <https://jjohnson3.typeform.com/report/uhYxMLfn/xgWwt8yqNzqStpQx>

Spanish* - <https://jjohnson3.typeform.com/report/hOVcYU8G/fEbB2YSTKVMQ7Xb9>

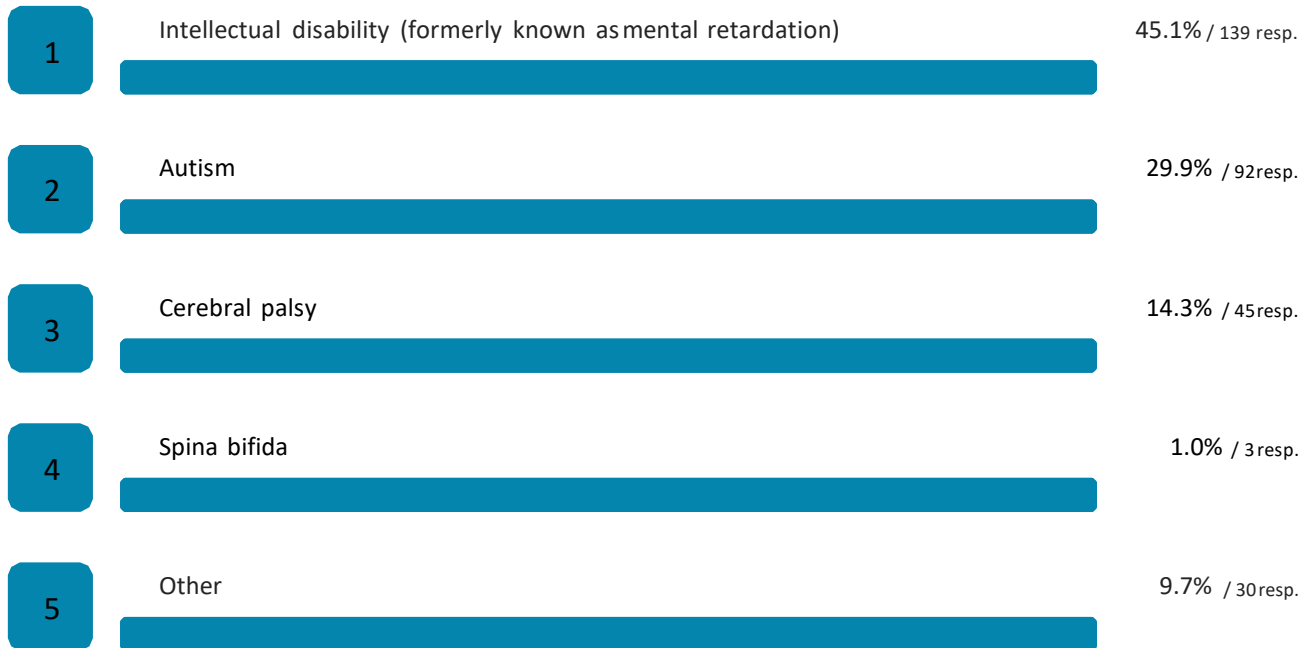
Google Spreadsheet can be found at:

<https://docs.google.com/spreadsheets/d/1Dd5ILN4Pml-o5ez7iCMutmywOLksZbhdRATw57SzNKc/edit?usp=sharing>

*The Spanish response to the survey was translated and added to the results in this report.

Question 2 What is the family member's primary developmental disability?

309 out of 309 answered

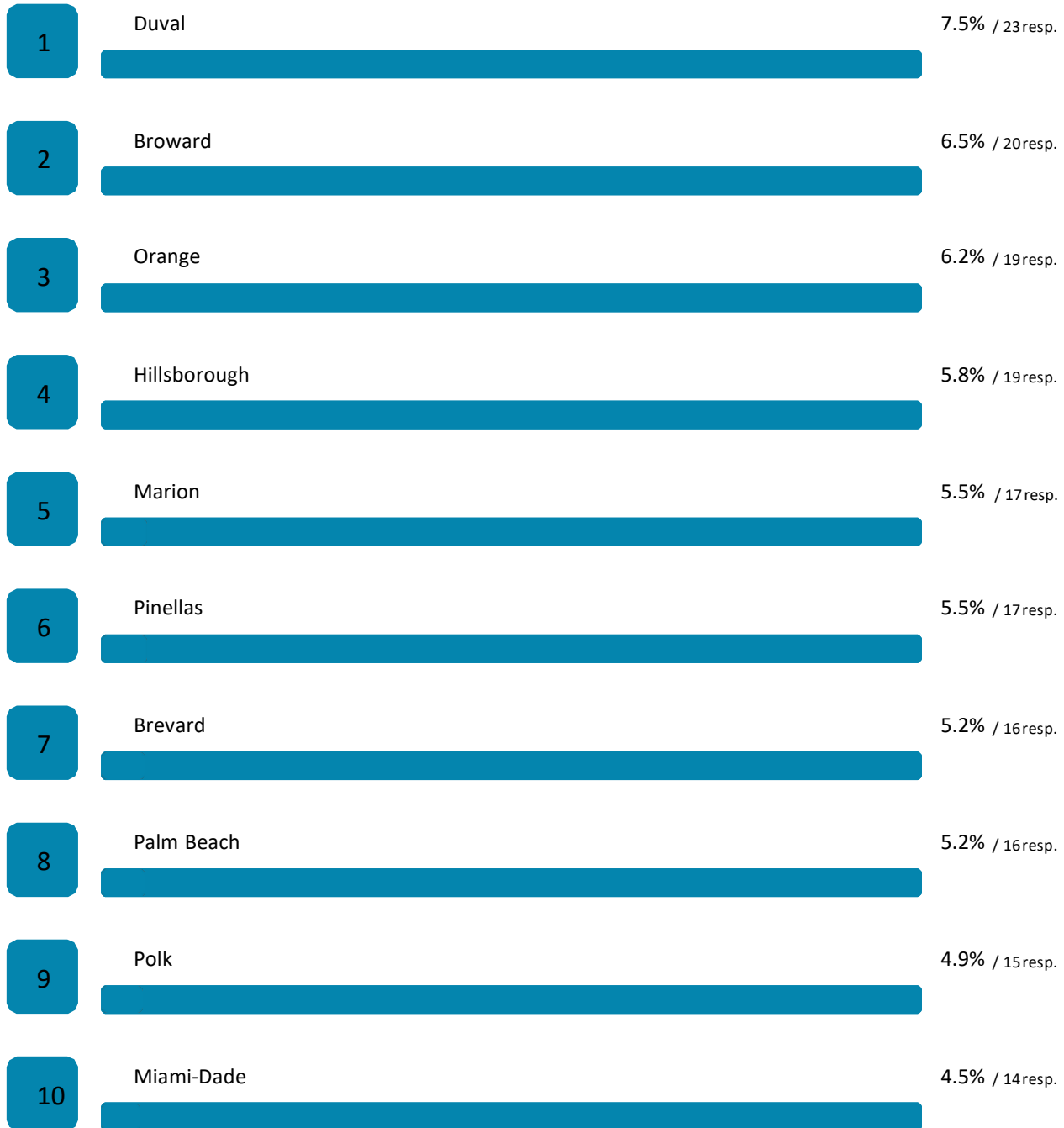


Family Member's primary developmental disability of respondents that selected 'Other':

Angelman Syndrome (4 resp.)	Down Syndrome (4 resp.)	Traumatic Brain Injury/TBI (2 resp.)
Alzheimer's	Brain aneurysm/stroke	Brain injury
Dementia	Ehlers Danlos Syndrome Hypermobility	Head Trauma
4 hip-placement mobility limited	Low IQ....delayed mental and emotional progression	Mentally challenged; doesn't talk or hear
Mental illness	MULTIPLE, HYDROCEFALIC, BLIND, CP, PHYSICAL MENTALLY DISABLED.	Muscular Dystrophy
Muscular Dystrophy (CMT) (Mitochondrial disease)	Near drown	Parkinson's
88 years old husband ~ Renal failure~ 14 yrs. on Dialysis m-w-f. He was given his 2 covid vaccines at dialysis but, I cant leave him to go get mine until I can go to my pharmacy a block away like I do for my flu shot. I'm over 65 too, If I go down, my husband is in a home :(Reyes syndrome	stroke survivor, weakness on right side, wheelchair bound, blind
Substance abuse	Totally physically impaired	

Question 3 What county do you live in?

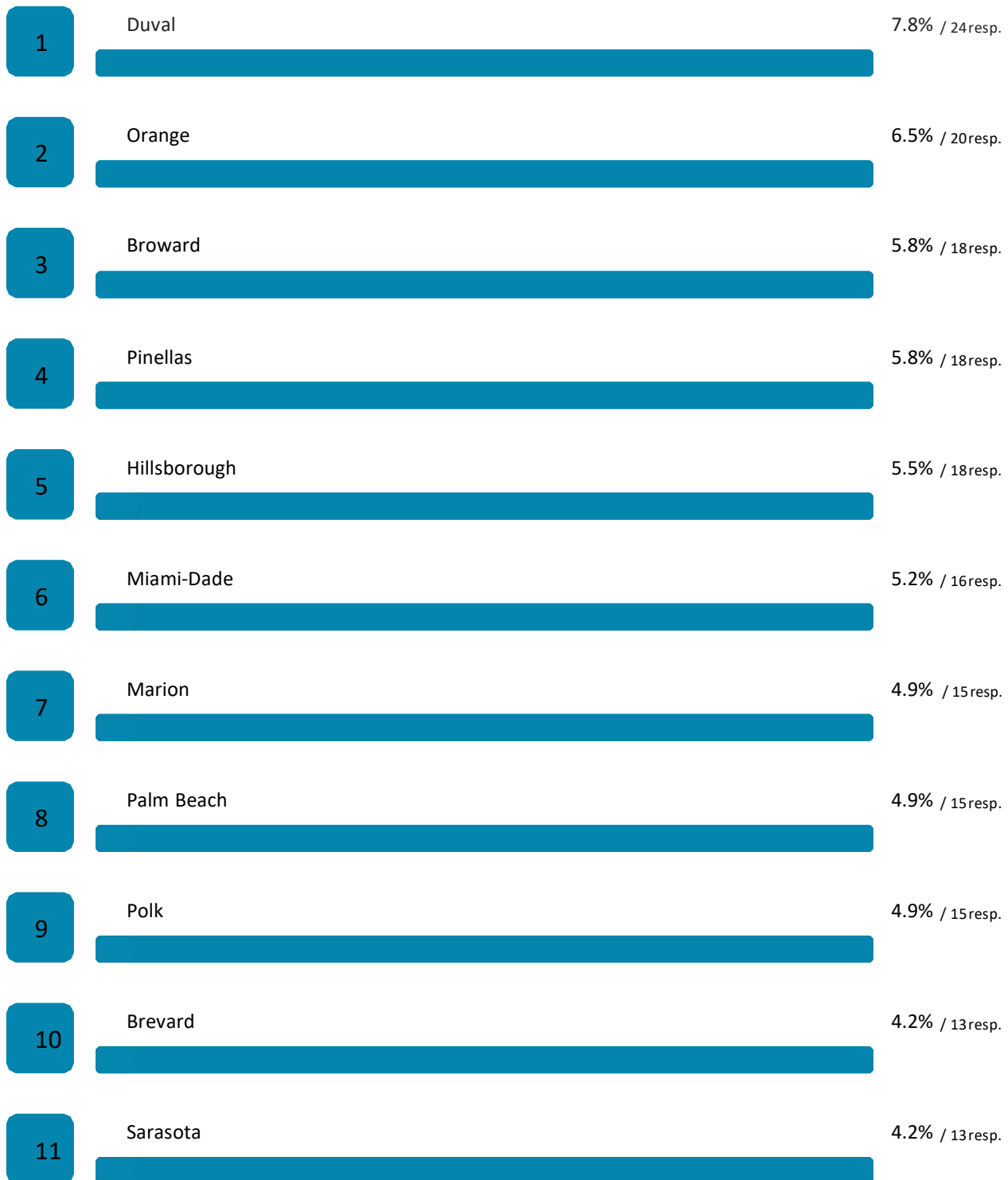
309 out of 309 answered



Number of Responses	County
12	Sarasota (1 County)
10	Leon (1 County)
9	Lee (1 County)
8	Clay, Santa Rosa, Volusia (3 Counties)
7	Alachua, Pasco (2 Counties)
6	Collier (1 County)
5	Okaloosa (1 County)
4	Escambia, Hernando, St. Lucie, Sumter (4 Counties)
3	Charlotte, Osceola, Putnam, Seminole, St. Johns (5 counties)
2	Citrus, Flagler, Gadsden, Highlands, Indian River, Levy, Martin, Suwannee (8 Counties)
1	Calhoun, Columbia, Franklin, Lake, Manatee, Nassau (6 Counties)
0	Baker, Bay, Bradford, DeSoto, Dixie, Gilchrist, Glades, Gulf, Hamilton, Hardee, Hendry, Holmes, Jackson, Jefferson, Lafayette, Liberty, Madison, Monroe, Okeechobee, Taylor, Union, Wakulla, Walton, Washington (24 Counties)

Question 4 What county does the person you care for live in?

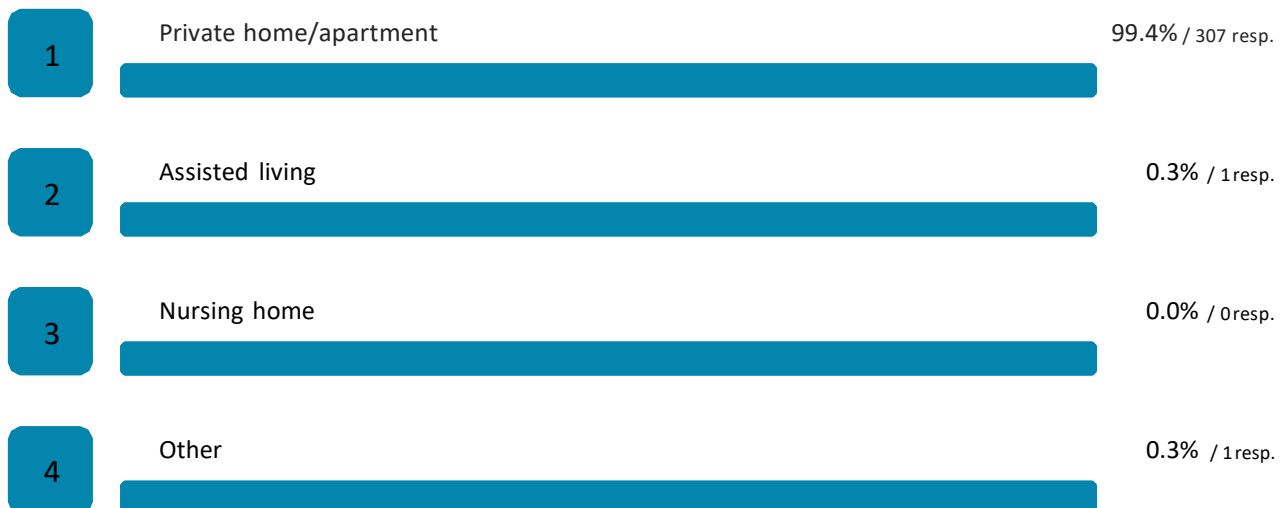
309 out of 309 answered



Number of Responses	County
10	Leon (1 County)
9	Lee (1 County)
8	Alachua, Pasco, Volusia (3 Counties)
7	Santa Rosa (1 County)
6	Clay, Collier, Escambia (3 Counties)
5	Okaloosa, St. Lucie (2 Counties)
4	Hernando, Sumter (2 Counties)
3	Charlotte, Indian River, Martin, Osceola, Putnam, Seminole, St. Johns (7 counties)
2	Citrus, Flagler, Gadsden, Highlands, Suwannee (5 Counties)
1	Calhoun, Columbia, Gilchrist, Lake, Levy, Manatee, Nassau (7 Counties)
0	Baker, Bay, Bradford, DeSoto, Dixie, Franklin, Glades, Gulf, Hamilton, Hardee, Hendry, Holmes, Jackson, Jefferson, Lafayette, Liberty, Madison, Monroe, Okeechobee, Taylor, Union, Wakulla, Walton, Washington (24 Counties)

Question 5 Where do you live?

309 out of 309 answered



Residence of respondents that selected 'Other':

My own home

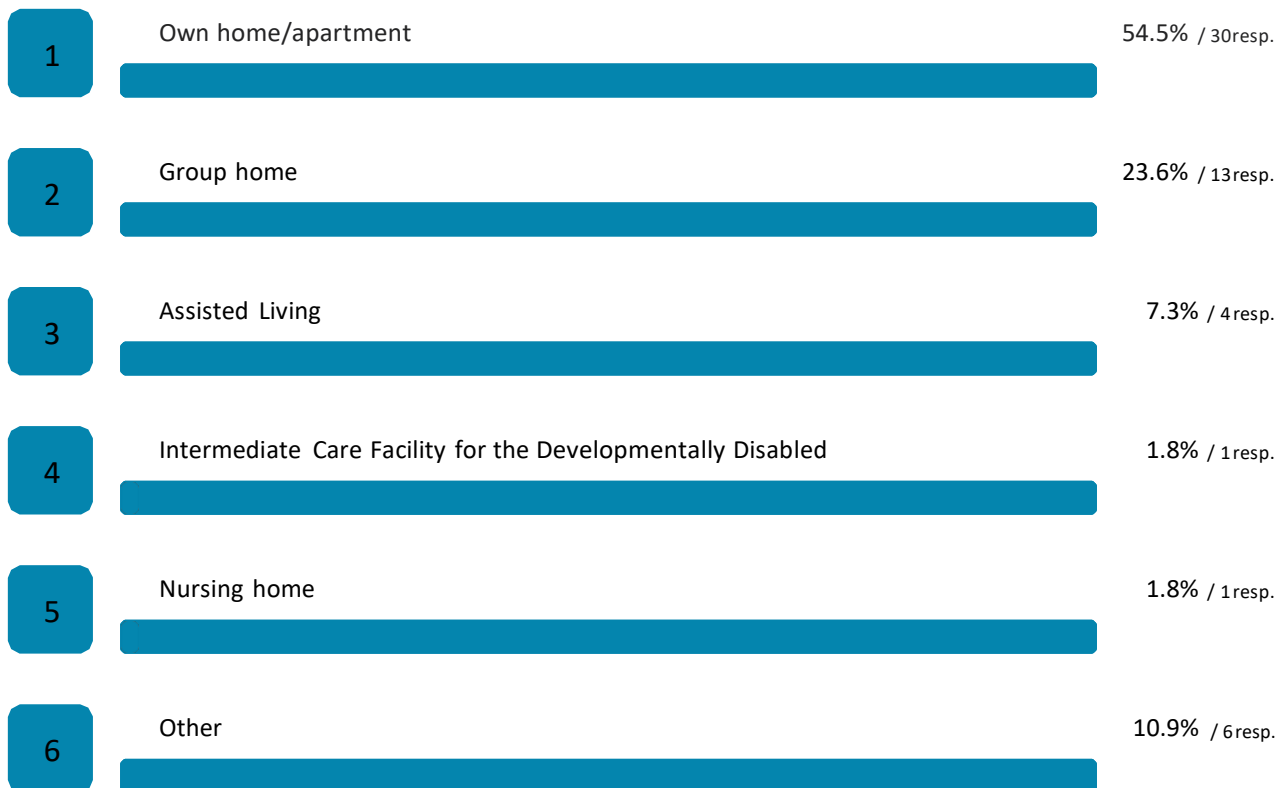
Question 6 Does the person with a developmental disability live with you?

309 out of 309 answered



Question 7 If no, where does the person with the developmental disability live?

55 out of 309 answered



Residence of person with developmental disability of respondents that selected 'Other':

ARC Village	Father	Friend's home
Her family home I'm companion caregiver/part time	Parental home	Rents home

Question 8 What is your age?

309 out of 309 answered



Question 9 What is the age of the person you care for?

309 out of 309 answered



Ages of the person you care for of respondents that selected 'Other':

Number of Responses	Age Range
13	1-19
77	20-29
95	30-39
1	10-75

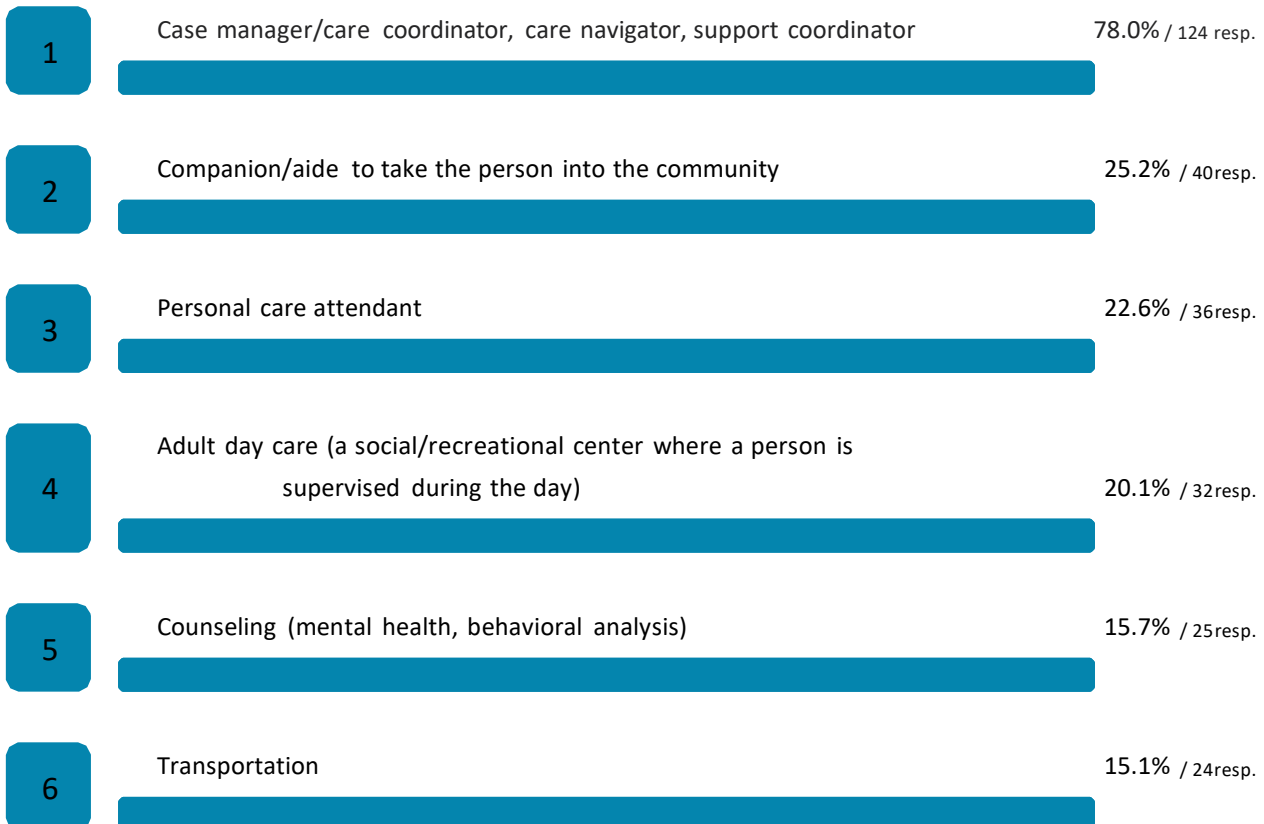
Question 10 Are you currently receiving services through any program?

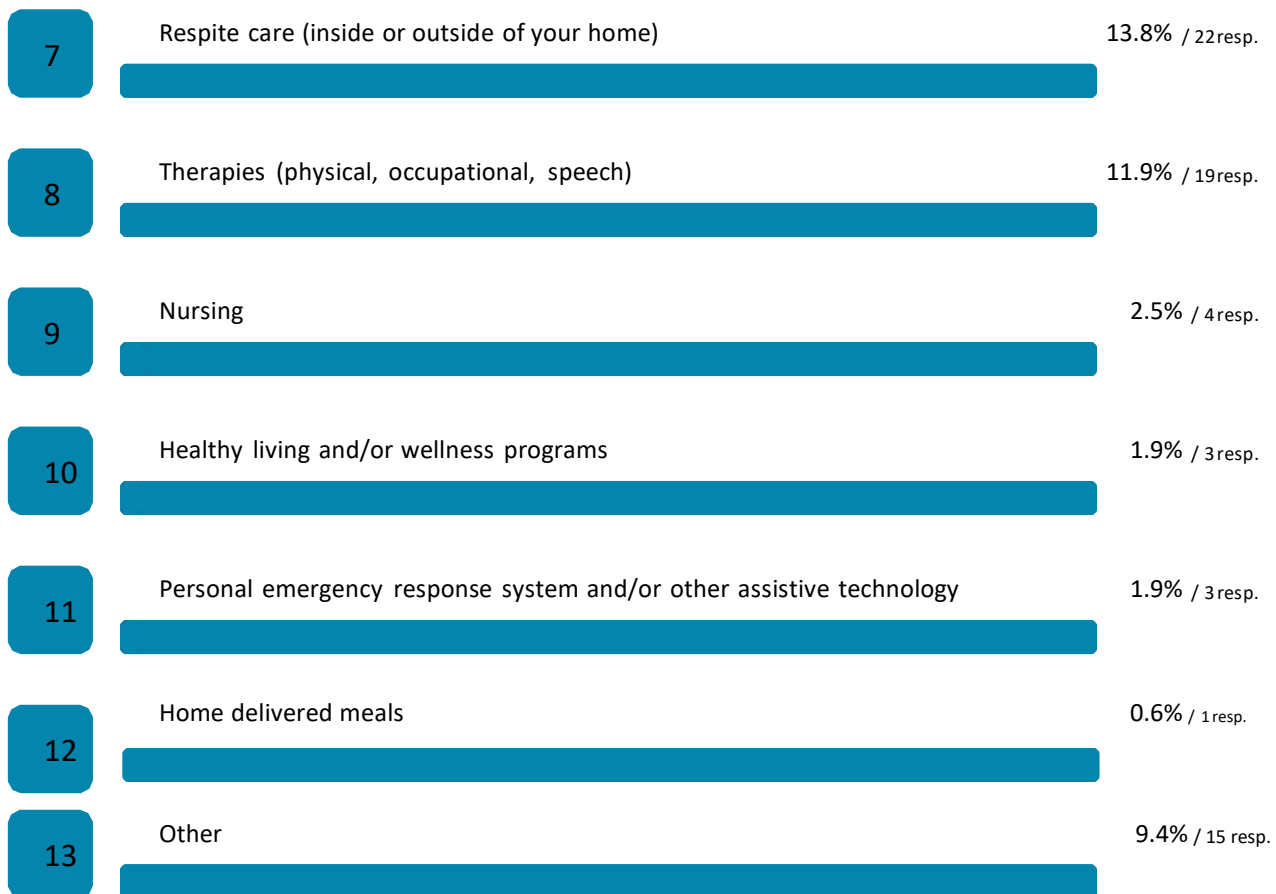
309 out of 309 answered



Question 11 Please mark any services you are currently receiving.

159 out of 309 answered





Services you are currently receiving of respondents that selected 'Other':

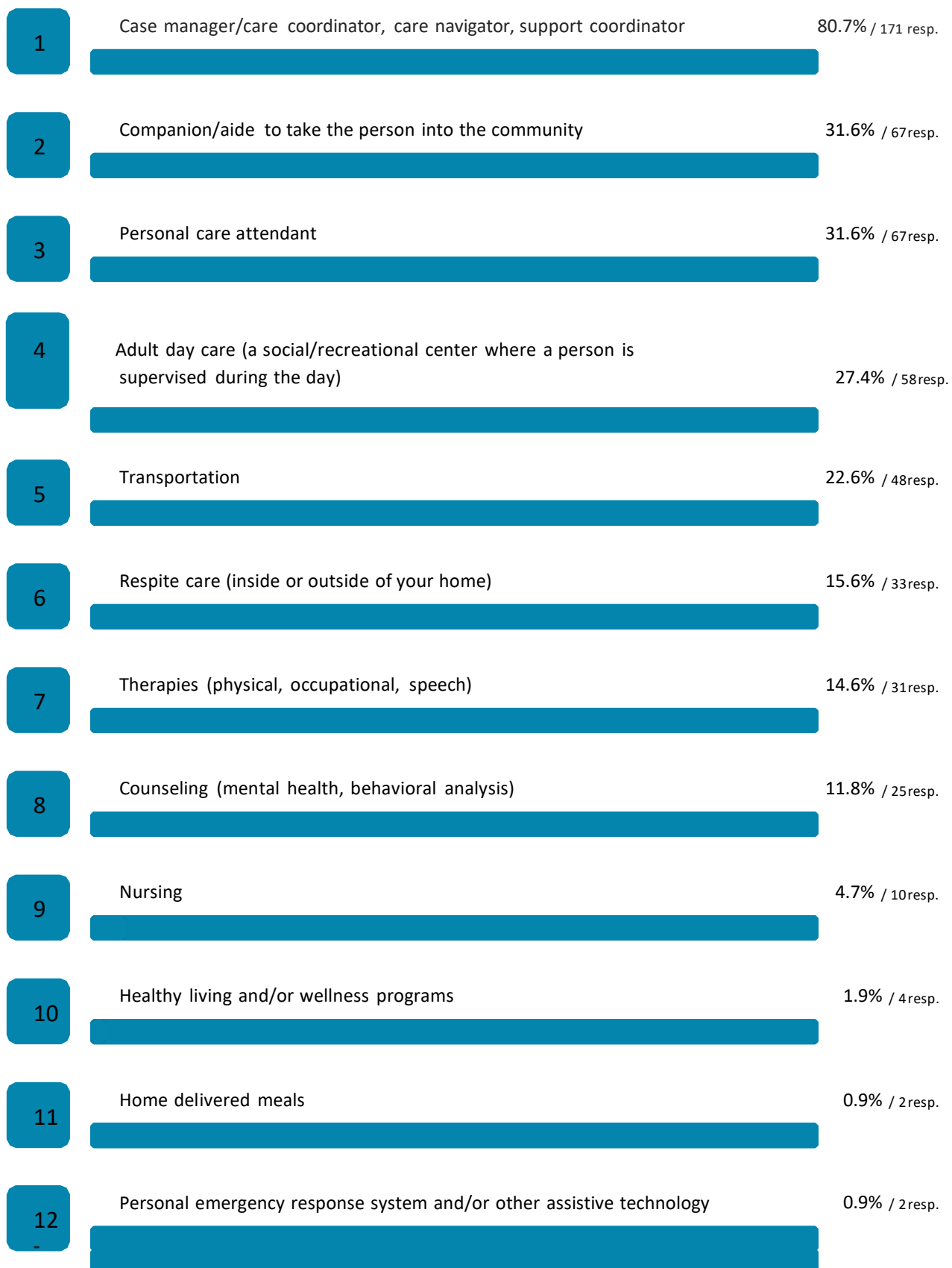
CDC+	He receives food stamps and SSI support	a grant that is reapplied for every 2 months for my son to attend the ADT
Group dances with supper and Proms....Karaoke.	Help with household chores	Helping people succeed
in home support services	Job training	medicare/medicaid
None (3 resp.)	PCA	I am on Medicare . I don't receive services but she does. I need a personal trainer that is what I need
Speech therapy and counseling are paid for out of our pocket, so while it is a service we pay for it ourselves		

Question 12 Is the person with the developmental disability currently receiving services through any program?
309 out of 309 answered



Question 13 Please mark any services the person with the developmental disability is currently receiving.

212 out of 309 answered



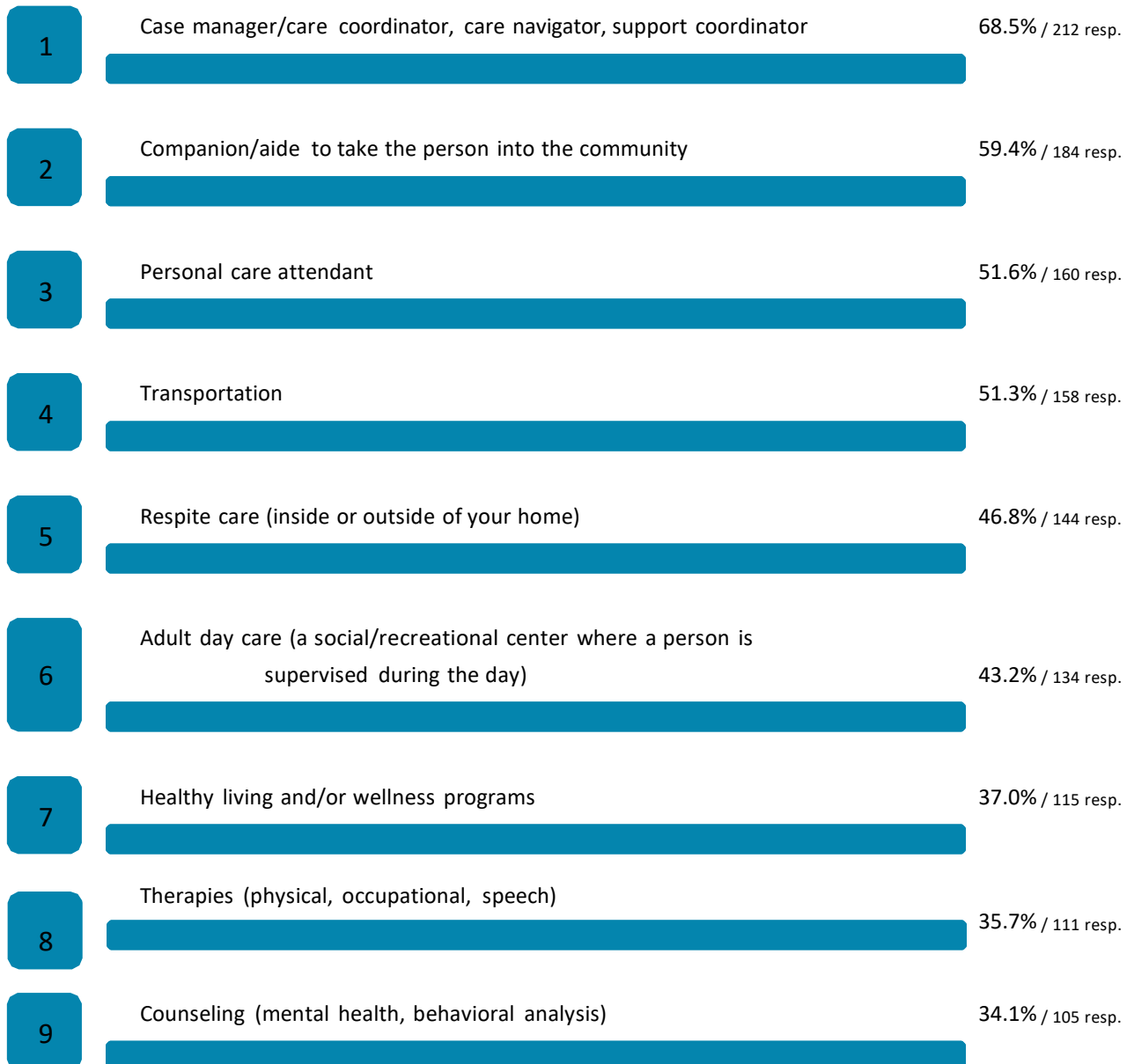
Services the person with the developmental disability is currently receiving of respondents that selected

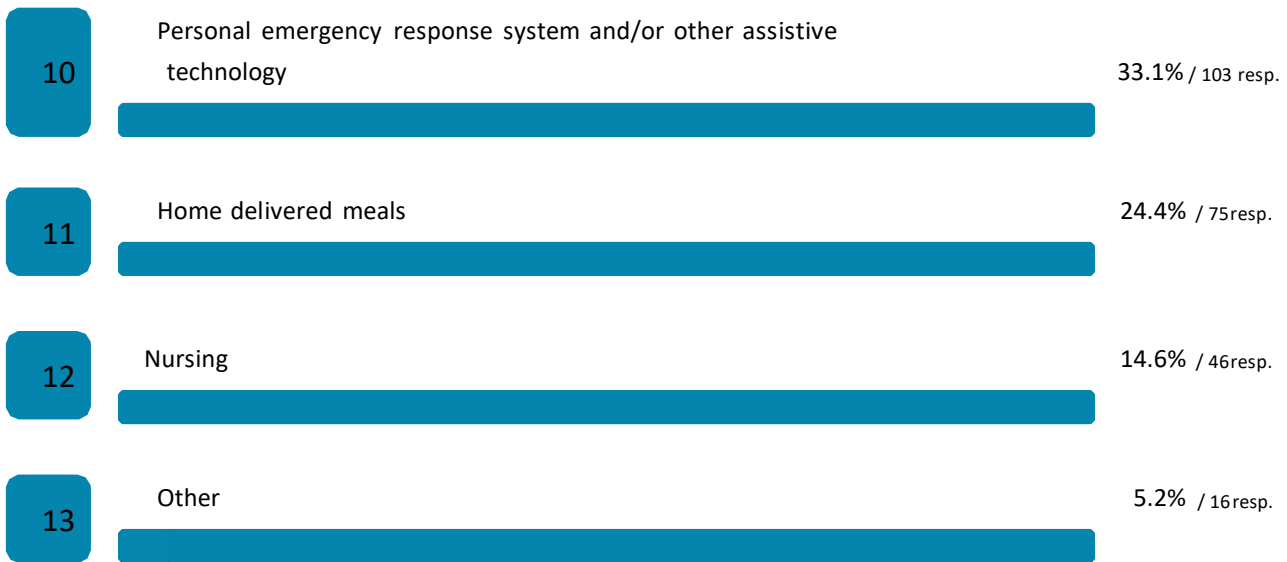
'Other':

Agency for Person's with Disabilities	Helping people succeed	In home support
Job training	medwaiver, medicaid	Most services are through the ALF. Waiting on medicaid funding
Scat plus take him and his walker on their lift to dialysis and some DR. appts.	SSDI	SSI
SSI and food stamps	virtual ADT/ADC "classes" via zoom	

Question 14 Mark any services you believe you will need as both of you age.

309 out of 309 answered





Services you believe you will need as both of you age of respondents that selected 'Other':

Don't know	Employment coach	Group home
guardian advocate	help with financial management	help with housing
Housing (2 resp.)	IDD facility	Job training & placement or socialization at a day center
Legally blind now, will need additional services	N/A	None
Same as now for our son, more assistance maintaining and managing his home	Supported employment	supported living in a residential community

Question 15 Do you know where to access information for future services you may need?

309 out of 309 answered



Question 16 Are you familiar with the local Area Agency on Aging in your area and what it does?

309 out of 309 answered



Question 17 Are you on a waiting list for services?

309 out of 309 answered



Question 18 Have you applied for services for your adult child that are funded for aging adults, but because you are receiving services from the Developmental Disabilities Waiver you are unable to access the services you need?

309 out of 309 answered.



Question 19 What are your greatest concerns as you and the person you care for continue to age?

299 out of 309 answered

What are your greatest concerns as you and the person you care for continue to age?	
1.	A lonely life for my child.
2.	A place for him to live and something to do during the day
3.	A place for us
4.	Ability to care for aging child
5.	Ability to care for her if she falls and hurts/breaks a hip/leg/ankle/foot.
6.	Accessible services living a rural area.
7.	Although my son is a teen - I am 50 years old and I am very concerned about who will take care of him as I grow older plus my family has a history of Alzheimer's so I want to make sure his needs will be well taken care of.
8.	Always, coordination/management of my daughter's services and care after I am gone
9.	An adult day program and group home that can meet his needs. A place where he is happy and well-cared for that can work with his significant behaviors and ensure that he can participate in the community. Want to ensure that this continues after I am gone.
10.	Appropriate care
11.	Appropriate medical and nursing care without having to live in a nursing home.
12.	are not being taken care of properly and adequately. less staff, lesser quality care and staff. and as funds continue to be cut, continues to be even worse than it is now.
13.	As I age, I don't have the energy to provide round the clock care.
14.	As I am getting older, I don't have as much stamina.
15.	As I get older and sicker, I worried about how my 2 adult autistic sons would manage their lives without people taking advantage of them. Housing, food, medical, etc.
16.	As I get older how will I pick him up transfer him to vehicles my back is already pinched in 6 vertebrates how do I keep this up
17.	Assisted living and funding
18.	Availability of quality care
19.	Because of COVID, She isn't attending Her ADP. Not sure how I will be able to care for Her. She needs care with all ADLs. Thinking Group Home, or other will be best as I age.
20.	Been on APD wait list for 15 yrs. He's now an adult. Need waiver program assistance soon
21.	Being able to continue to care for him as I age.
22.	Being able to continue to care for my son at home without support. It is already very difficult.
23.	Being able to keep close contact with my Downs daughter when I am unable to care for myself.
24.	Being able to meet the needs of our son and preparing for him after we are gone.
25.	Biggest worry is I won't be able to care for my daughter and she will end up in a place that won't know or understand how she is

What are your greatest concerns as you and the person you care for continue to age?	
26.	Both my husband and I are over 65 y/o and are the sole caregivers of our daughter who has multiple developmental disabilities and intellectual disabilities. Both of us have our medical conditions and our strength is getting less by the day. We have a caregiver who comes some hours a day but many days we don't have anyone.
27.	Care
28.	care after death
29.	Care for him as I get older and after I die, and as he gets older.
30.	Care/support for our son
31.	Caregiver support and respite.
32.	Concerned about caring for him as I get older and both our needs increase.
33.	Continuation of care.
34.	Continued care for my son, what is going to happen to my son if we die. He gets 15 hrs per day X 7 days.
35.	continued community involvement
36.	Continuity of care to the level she has now.
37.	Cost of services
38.	COVID restrictions right now no services available, and haven't been available for the past year. Who will take care of my adult disabled son when I die.
39.	Currently, there are no proper services provided for the developmentally disabled, making it necessary for the aging parent to play this role. As an aging parent, this is not sustainable. I am not aware of any provisions made by APD to provide the required comprehensive services needed by aging developmentally individuals, nor of any plans to develop this urgent need. It is critical to point out that the developmentally disabled are living longer and will outlive their parents. The State is not prepared and is not allocating the necessary funding to create the plan and establish it.
40.	Cut out in service
41.	Decisions on who will care for my son when I become unable to do so
42.	decline in health and caregivers unable to care for
43.	Dying
44.	dying before he is placed
45.	Ensuring they have a quality of life
46.	Everything
47.	Fear of my husband and me dying and leaving our autistic adult twins without appropriate housing & care.
48.	Financial and physical safety
49.	Financial help and adult care
50.	Financial needs for personal items for my child. Someone to care for him when I need to go to a Mtg. Etc.
51.	Financial stability and family to take care of her in case something happens to me
52.	Finding an advocate or guardian to replace me
53.	Finding competent, caring in home support people for my son.

What are your greatest concerns as you and the person you care for continue to age?	
54.	Finding good, reliable at too low a wage.
55.	FINDING SAFE QUALIFIED STAFF
56.	Funding will be cut! important to give my loved one the proper care he needs to have quality care. The services are not adequately funded now!!
57.	Future living arrangements
58.	Getting a mental health provider at a reasonable price
59.	Guidance
60.	Having a companion to take her out.
61.	Having a residential community with supported living services available for my adult son so that there are multiple opportunities for growth, social engagement and integration into the greater community in a safe enriched environment.
62.	Having qualified people to care for her. Day programs that are accessible. Nothing in Titusville for her.
63.	Having someone to take care of my son and his finances when as parents we are no longer able to support him
64.	He will accept help and not turn down except for already in place
65.	He will fall prey to unethical people.
66.	He will fall through the cracks in the system and not be taken care of
67.	He will still continue to get services, that family who will be caring for him will continue to process medicaid and all forms that go along with a child with a disability
68.	Health
69.	Health and safety
70.	Health insurance, transportation and housing
71.	Health, replacement of caregiver, need for living facility
72.	Her care in all sort of situations
73.	Her having the same quality of life that she has now
74.	Her not being cared for or her wishes not being respected when I'm dead
75.	her not having support services when something happens to me
76.	Her not having the help during emergency and not being able to get to her. Getting all the services she will need in place when I'm no longer here.
77.	Hi sorry health and happiness. I can't provide all care now but at some point may not be able to. He is on medwaiver list but I still not getting services now.
78.	His care if I die
79.	His independence for living alone because I am getting older and it is more difficult for me to take care of him.
80.	His isolation/lack of community interaction.
81.	Home health care services and transportation
82.	Housing and long term oversight to her care and services

What are your greatest concerns as you and the person you care for continue to age?	
83.	Housing in the future. Quality of day programs
84.	Housing, the ability for independence, money management.
85.	Housing, mental health
86.	How long I will be able to care for my daughter, where she will live when I am gone, money for any services she may need beyond what is provided by the community she may live in.
87.	how to keep my wife at home and well if I become incapacity even for a very short time.
88.	How to survive financially while caring for my disabled daughter? How to get Help with care for my daughter while I work? Who will take care of my disable daughter if something happens to me? How to become a paid caretaker for my daughter?
89.	How we will manage.
90.	I am concerned that he will need a male caregiver, someone physically able to handle outbursts or meltdowns in public.
91.	I am finding it more difficult to take care of him as I need more care myself.
92.	I become unable to care for my child any longer
93.	I die before him
94.	I don't want him to be a burden for his other siblings. He is autistic with some mental delay but loves his family, when my husband and I are gone if he lives with one of his siblings I wish they can have some respite because he talks non stop and sometimes misbehaves just for attention.
95.	I have cancer and if I die, who will care for my adult child
96.	I have significant health issues that prevent me from working but got declined from social security because my income slowly declined over the years, given that I've been a long term caregiver, so they said I did not apply in a timely manner. Currently I have a disability policy but that will end in 5 years. I'm wondering if I would qualify to tap into my ex husbands social security given that he's never stopped working. I am too exhausted to figure this out & am always behind on ALL other things related to caring for my son. Is there someone in your office that knows this "fringe" portion of social security benefits? I have a hard time just taking care of things around the house because of my health, & my enjoyment in life is at a major low point because I just cannot BE & do everything like I used to be able to do. I remember meeting other older moms, when I was younger, hearing them express that they had gone "downhill." I won't put him in a "home" because he LOVES being with me, in the friendly community in which we live. ~is there a person "with a passion" that would kindly help me "research ideas", talk with me about "options", or help me complete paperwork. It is not too difficult, but is for me to do alone because I'm weak, & truly tired of doing all of these deadlines by myself for so long.
97.	I may not be around to guide her in her day to day decisions
98.	I need someone to check on him regularly, grocery shop and provide occasional outings as well as make sure he gets to and from a part time job when able to go back to work.
99.	I never have any time off, I'm 65 and its 14 years and I'm getting very tired and depressed, and this was before Covid 19.

What are your greatest concerns as you and the person you care for continue to age?	
100.	I no longer can care patiently for my brother in law. I am not a safe driver, on pain pills for chronic pain. He has not had adult day services since pandemic and has been with us full time. My husband still works in a local hospital and I try to do what Rick needs to decrease the burden on him. I am depressed and overwhelmed! We were on the waiting list for 16 years before we got any help. The so called services have been inadequate and unreliable. Still feel his total care needs are all on me. I get no help from his siblings and feel dumped on by them. My husband will continue to work forever because he wants no part off this burdensome care giving. Otherwise our long-term marriage is good, we are just tired of 19 years of high maintenance for his brother. We just started with his 5th or 6th case coordinator, I can't even get use to the name of them and they are replaced by another. His last supportive living coach would bring her newborn infant with her to take Rick grocery shopping! Once again he is not the first priority of someone getting paid to help him. Florida should be ashamed of the way that this dependent population are treated!
101.	I will be unable to visit him, respond to his needs/requests, manage his money, interface with agencies that serve him.
102.	I will die before my daughter.
103.	I will no longer be able to care for him due to my advanced age.
104.	I will no longer be able to handle things on my own and my son won't know who to reach out to in order to received assistance.
105.	I will not be able to take care of him.
106.	I won't be able to care for myself and son.
107.	I won't be here and none of his siblings can/will help
108.	I won't be able to continue caring for her.
109.	I worry most that either my son or I, or both at the same time, may encounter future health problems that will over tax our support system that is working well currently.
110.	I worry that when my husband and I die our son will lose his services if he moves to another state to be with other relatives, but they could not care for him without services. His Medicaid waiver is not portable. He would have to enter a group home, but being in a wheelchair and legally blind makes me worry he might receive the amount of help and support he needed.
111.	If I can keep up
112.	I'm getting tired and will need a break.
113.	I'm WSC. Young adults not have guardianship options.
114.	Impossibility to visit with each other because of distance and deteriorating health.
115.	In home services
116.	Inability to continue to provide care at the necessary level, including finding employment for her.
117.	Inability to perform daily, necessary duties to live independently and maintain our house.
118.	Independence
119.	independent living for him that fits his needs
120.	Independent living skills to transition into community living on her own with supports. Transportation to work, shopping, and medical appointments.
121.	It is becoming physically difficult to manage her. Fear of falls. Difficult getting her to walk and outside. Can not leave alone for a minute

What are your greatest concerns as you and the person you care for continue to age?	
122.	Kasey is going to continue to require dental and medical services outside of what the waiver and Medicaid pays for. Additionally, Kasey will continue to require medically necessary health services from specialists that the iBudget waiver does not cover. Such treatments are not covered by Medicaid either.
123.	Knowing that he will be loved, respected and cared for as he has no voice...
124.	Lack of qualified staff/employees of providers providing Personal Care Services and Supported Living Services for my son.
125.	Left alone she makes poor choices for herself.....who is going to watch over her when I am gone...she does not drive...how will she get to places she needs to go...help her with finances
126.	less independence, more care needs
127.	living arrangements for my son and finding a job and leisure activities to keep him busy
128.	Living in community independently. Better communication about resources
129.	longterm housing stability
130.	Loving care and assistance /support for my daughter, medical, social and emotional
131.	Main concern is his ability to live alone after I am gone. I handle all of his finances, shopping, transportation. I bought his house. He is high functioning. I am financially and physically able to handle all now and for probably next 7 years until I plan to retire fully.
132.	Medical and living places
133.	Mental health issues
134.	Mental Health Services, Transportation, Medication, Nutrition Program, Exercise Program all for me
135.	My ability to care for my child.
136.	My ability to continue to care for him
137.	My ability to physically perform daily care for him. I am 4'11 inches and weigh 83 pounds with severe arthritis. Eric is 6 feet, blind, profoundly intellectually impaired and requires assistance with every aspect of his day (feeding, toileting, walking,). He is nonverbal and extremely aggressive when he doesn't understand what is happening to him and combative towards me for some essential daily care routines (clipping nails, putting on a band-aid, etc).
138.	My adult son needs a place to live with amenities such as prepared meals, and friends, and a helper.
139.	My concern is for my adult disabled child as he will need medical and residential services
140.	My concern is that my SIL keep using her muscles so they won't atrophy (i.e. walk at least a few steps). We are also concerned about finances to keep her where she is over time. She just moved from an ARC group home to assisted living and is thriving.
141.	my greatest concern is support services for her if something should happen to me, and my other concern is lack of programs for her to be involved in. no safety net if something happens.
142.	My greatest concern is who and where will my daughter be cared for. I would like her to stay at home where she has lived all her life.
143.	My greatest concerns are me not being there for her as we get older
144.	My husband and I will not be able to care for our daughter at all. It's difficult now, because we both have bad backs and I need back surgery, but can't have it done, because not having someone caring for our daughter is an issue.
145.	My inability to handle him

What are your greatest concerns as you and the person you care for continue to age?	
146.	My inability to help him manage his behaviors due to his ASD along with his OCD.
147.	My inability to provide the daily care needs for my son who needs meals prepared for, laundry, housekeeping, transportation, medical care management, social services management, etc.
148.	My physical ability to care for her 24/7. Her quality of life
149.	My son also has Epilepsy w/seizures. As I age I am no longer able to help him get up and certainly can no longer catch him or try to break his fall. Most likely within the next 2 years he will need to move into a group home.
150.	My son is taken care of and receives the services he needs.
151.	need for assisted living for my daughter, that is not covered because of medwaiver
152.	Need more hours for the Aide and Personal Care Assistant
153.	no adult day care programs so I can continue to work which will make us homeless. Need highly supervision adult care camps with behavioral trained staff so parents can work once age out of school. I also applied twice for crisis got denied and was told there is help for my kids when I become homeless. AOD does not care
154.	No family member to care for him.
155.	No one to manage finances, pay bills, order medicine, administer daily doses, schedule Dr appointments & provide reminders & transportation to appts. Shopping for food , etc.
156.	None at this time
157.	None right now
158.	Not being able to care for him
159.	Not being able to have the health and strength to take care of her.
160.	Not being healthy enough to care for my son by myself, I need help now and I can't even get respite care to allow myself to take a break.
161.	Not being physically able to care for myself and my adult son as we both age and our healths decline.
162.	Not knowing where he will live and what is available to him
163.	Obtaining services to replace my caregiving, abuse, neglect
164.	Ongoing health
165.	Our ability to physically take care of our son
166.	Our adult son is 25/7 care, feeding, incontinent, non communicative, meds, bathe, shaved, wheelchair, hosp bed.
167.	Our daughter has mild autism. ...asperger's...she can drive and do her laundry but only delivers food 10 hours a week. Does not like to socialize and is not a Florida resident at this time. Has a bit of odd and ocd... very overweight and has intestinal problems and pre diabetes. She lives out of town with an old boyfriend but is moving on and Hope she will move to Florida. She is safe though.
168.	Person I care for is an only child and has no extended family to depend on.
169.	Physical ability
170.	Proper care

What are your greatest concerns as you and the person you care for continue to age?	
171.	Providing care to my son for his showers and washing his hair etc continue to affect the arthritis in my back. I continue to provide this care to him even though it's painful because I love him and am concerned about bringing a stranger in to provide this service and care. I will be 50 years old this summer and want to begin to transition my son to get use to some one else providing this because someday I might not have the ability to do these kinds of tasks for him and he would be emotionally shocked if this was to be a sudden unplanned event such as if I got sick and hospitalized or passed away unexpectedly. My son is 25.
172.	Quality of care
173.	Quality of care and funding
174.	Respite
175.	Running out of funds for care
176.	Safe home and services to help
177.	Safety and assistance with help for proper care
178.	Safety, health, wellness not able to advocate for us myself, isolation, pain, lack of professional work ethic in personal help, money
179.	Safety, Quality of life, health
180.	Self care and living arrangement
181.	Separation
182.	Services will not be available.
183.	She does not adapt well to change and if she needs assisted living she may resist. She is very independent but cannot read or drive and has problems understanding complex ideas. She will need help with financial matters for the rest of her life.
184.	Simply that we continue to receive the service we currently have.
185.	Since I don't want her brothers to institutionalize her, who is going to care of her when I pass away?
186.	Socialization and HealthCare
187.	Someone to care for him after we're gone.
188.	Someone to care for my son when I die. Have someone who will.
189.	Someone to take care of my son when I die. Also, being able to help him stand up and sit down.
190.	Something happening to me and having no one to care for him
191.	Staying healthy enough to take care of my daughter
192.	Stopping the budget cuts from APD through CDC+ program!!
193.	Support for him to replace what we currently do for him and increasing physical needs as he ages.
194.	Supports after I am gone
195.	taking care of both our healthcare challenges day to day, doctor burnout, agency burnout, money, insurance, income
196.	That he can continue to live in our home.
197.	That he has a safe place to live
198.	That he will not be adequately prepared for trauma of being without our care and will not be able to implement a course of action without significant assistance. We have had few personal services provided for our son as he rejects offers of companionship and assistance, therefore he unaccustomed to receiving them.

What are your greatest concerns as you and the person you care for continue to age?	
199.	That he won't have the help he needs
200.	That I die before her
201.	That I die before my adult child
202.	That I will become too old/frail/ill to care for her or help her handle her basic ADLs as well as managing the paperwork organization involved.
203.	That I will die or get ill and worry what will happen to my son. Also if I can't afford 1:1 aide for his school I will not be able to work. Also when he turns 22 what will he do all day Basically I worry all the time
204.	That I will no longer be able to provide all that he needs. I worry great about what would happen to my son if I became seriously ill, had to be hospitalized, became physically disabled or died.
205.	That I will not be able to care for him
206.	That I will not be able to physically transfer her
207.	That I will outlive my sister and finding an appropriate living situation/facility for her. Also, I wonder when the best time will be to transition my sister out of my home into another environment.
208.	That I won't be able to meet my son needs as I am having to take care of my needs.
209.	That I won't be able to provide enough care for my son and services have been cut back even as I age and have more medical challenges.
210.	That I/we have no trusted individual or agency to serve as I the caregiver pass away.
211.	That my child will be forced to live in a group home or other facility
212.	That my husband and I will die and our son will be left to fend for himself.
213.	That my son will be helpless when I am no longer able to care for him
214.	That my son will become home bound with no friends and social stimulation. I also get concerned about my son in meal planning, medication distribution, medical care, grocery shopping, planning for and transportation to and follow up on medical appointments. It's very scary not having anyone to monitor and assist
215.	that no one will watch out for our adult child when we are no longer alive
216.	That our daughter will have to go into a group home as we age.
217.	That our disabled daughter will be well cared for.
218.	That our son will receive enough hours from the med waiver to enable him to live independently.
219.	That she will be supported and cared for medically and physically. And have a good life.
220.	that she will get the assistance she needs easily
221.	That she will not be able to live independently and work without support
222.	That the legislature will cut funding and services
223.	That the people in legislature will make Waiver managed care and my son will have no option but group home because that is the only way managed care can make money off him
224.	That there won't be anyone to take care of my child when I'm gone.
225.	That they continue to get the care they are receiving
226.	That we will be able to continue with in home care as we do now.
227.	That we will not be financially stable to survive. That our situation will continue to deteriorate and there will be no one to help us.

What are your greatest concerns as you and the person you care for continue to age?	
228.	That we won't come back home.....we agreed on this.
229.	That we would be taken care of, especially the person I care for, because he does not have any other family.
230.	The are 475,000 families in Florida who are aging with a loved one with a disability living at home. Once the care givers die (unless you dump them on a sibling which almost never lasts) there is no safe place for them to go. In group home and residential settings 82% are abused, hurt or killed. The group home workers only get \$10 an hour and the turnover rate is high. In seniors homes - the average cost of a month is \$8000 - but the workers only get \$10/hour - so who is getting all the money. In Florida if you go the Autism Housing Website - there are only 5 places in the entire state of Florida listed to place a loved one with a disability who can not live independently - the waiting lists for any "good" (oxymoron) group home is 10 years. There have been 10000 studies to make people "aware" of this situation in the last 5 years including a huge one by ARC. NOBODY CARES. So the only option is letting them go on the street
231.	The cost to take care of him will be more than we can afford
232.	The lack of appropriate and well funded care in programs for the developmentally disabled in Charlotte County.
233.	The lack of dedicated apd med waiver support coordinator and services in Florida. Flat line.
234.	The main concern is having someone take care of her, provide her with everything she needs and that she is well treated.
235.	Their wellbeing when I am not here. Ability to function in society.
236.	There will be no assistance
237.	To be able to care for him
238.	transitioning son from living with us to a group home
239.	Travel and assistance in home
240.	type of care given don't want a managed care company to come in for care. gone thru that before in 70's and caregiver was put in jail for stealing benefits and supplies from disabled. higher up's don't get supervised on their positions.
241.	Unable to care for my child
242.	Very limited services in Titusville. No day programs.
243.	Waiting on the disability waiver. Been on wasting list for Just under 10 years.
244.	We desperately need respite services
245.	We have been on a waiting list since they were 3 and they are now 16 and we are still on a very long list. Will we ever get help???
246.	We have no family here so my greatest concern is someone to just be with my son.
247.	we moved here 5 years ago and don't really know anyone. All of our family is in NY. Our son will need a caregiver, 24/7. Waiting list to receive med waiver is so long to get permanent services
248.	We will not be here for our daughter
249.	welfare for adult when I no longer can provide
250.	What happens to her when I'm gone.
251.	What happens to him after I'm unable to take care of him properly
252.	What happens to our dependent when we pass on. And whether we'll be able to care for her.

What are your greatest concerns as you and the person you care for continue to age?	
253.	What happens when I am no longer here or any other family friends
254.	What happens when I die
255.	What happens when I die
256.	what happens when I'm gone
257.	What he'll do when I'm not here to care for him
258.	What is going to happen to him when I'm gone?
259.	What will become of him when I am gone. Who will provide all of the help he needs since he is very dependent of others - not self sustaining.
260.	What will happen to both children as my husband and I get older and have problems managing them
261.	what will happen to her when I am gone
262.	what will happen to her when I'm no longer able to care for her
263.	What will happen to him when I'm gone
264.	What will happen to my child when I die?
265.	What will happen to my son when I die
266.	What will happen to my son when my husband and I are gone.
267.	What will happen to my son when we can't take care of ourselves or we die.
268.	What will happen to the person I care for if and when I am unable to care for him.
269.	What will happen to them when I die
270.	What will happen when I die.
271.	What will happen with my brother if something happens to me
272.	What would happen if I am unable to assist with her care or if I should die before her.
273.	What's going to happen when I'm gone
274.	When 1 of us has to be hospitalized. When I pass away. What happens if I get cancer or stroke. Who will take care of her when I'm gone. Will she be abused. Will she be mistreated or taken advantage of.
275.	When I die, who will provide future care
276.	when I'm gone or unable to care for her, who will and will she be safe and well cared for and not abused. I stay awake at night thinking about this.
277.	When we're gone, what's going to happen to my son. Who will take care of him??
278.	Where my son will live once I'm gone or can no longer care for him.
279.	Where will he live when I'm gone
280.	where will I live after someone pass away
281.	Who is going to take care of my Daughter after I pass away.
282.	Who is going to take care of my son when I can't.
283.	WHO WILL CARE FOR HER WHEN I AM GONE AND SHE AGES
284.	Who will care for her when I can no longer do it.
285.	Who will care for him
286.	Who will care for him the way I do? What will he do without the loving home he knows.

What are your greatest concerns as you and the person you care for continue to age?	
287.	Who will care for him when I'm not able
288.	Who will care for my 2 adult disabled dependents when I can no longer care for them.
289.	Who will care for my child when I am unable to do so.
290.	Who will care for my child when I die
291.	Who will continue to care for her when we are no longer able to. Will we be financially able to handle caring for her after we retire.
292.	Who will oversee his affairs, Trust, etc. if I am not able.
293.	Who will take care of him
294.	Who will take care of him and make sure he is safe and healthy when I am no longer able to. How long will I be able to care for him. How can I continue to advocate for every single thing he needs to be safe and healthy and stay in his community. It gets physically and mentally exhausting to fight for and justify everything. It seems there are more and more layers of paperwork and bureaucracy for my son to receive any help. New rules for dentist.. he hasn't been able to get into one since they require us now to go through dental groups.. that have their own set of rules. Why do they keep making everything harder and harder for the caregiver to give care?
295.	Who will take care of him when we are gone.
296.	Who will take care of my child when me and my wife are gone.
297.	Who will take care of my daughter.
298.	Who will take care of them when I can't
299.	Who will take over care management and decision making

Question 20 If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?

291 out of 309 answered

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
1.	????
2.	A centralized platform showing all choices of services, agencies, equipment, supports etc. Should be presented in icon format for ease of navigation. And, within each link, clear instruction steps
3.	A daily program with transportation for my son.
4.	a glassdoor to a dramatic outdoor therapy lagoon...showtime stage.
5.	Access to community resources that would benefit her
6.	Access to more persons qualified to care for her. Shortage of good PCA providers. More hours of care
7.	Access to social services
8.	Activities
9.	Add more hours for the Aide and Personal Care assistant
10.	Additional service providers and options
11.	Adult living facility that encourages independence and provides strong social environment

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
12.	After 14 years ~ I don't even know...You become a clock watching robot, for the next chore, pill, shower or appointment.
13.	APD move faster on requests and funding
14.	As a CDC+ representative, to be paid for the time invested in managing services and provider payments
15.	Assistance to us, the caregivers, on how to help son transition to supported living and being open to other services offered.
16.	At the ARC Village I need to talk with other people who have been through this and gain their wisdom along with someone who can help with our concerns
17.	Availability for temporary care for no more than a week. This has been impossible for us to secure.
18.	Availability of and Access to skilled, knowledgeable, professional help who will work for the pecuniary wages of the waiver
19.	Availability of help and resources
20.	Availability of nursing-have service but lack of nurses
21.	Availability of respite care.
22.	availability to services
23.	Be more informed
24.	Be more knowledgeable about services that are offered.
25.	Better access to information about resources, fewer obstacles to obtaining resources, more providers
26.	Better access to services and support
27.	better communication on services
28.	Better equipment to safely take care of him at home. Home modifications
29.	better funding for services
30.	Better health
31.	better information given by medwaiver about cfc plus+ and how it actually works for a single parent with no other family supports
32.	Better job coaches that will stay in touch with employers and better education to employers who hire people with disabilities and be more tolerant and more in touch with care giver
33.	Better knowledge what to do, how to do it, and where to get help if needed.
34.	Better medical and especially dental choices
35.	Better physical health
36.	Build a stronger network of support people for him.
37.	Capable of continued care
38.	Change the whole System as to the ways and means how they treat Persons with Developmental Disabilities and their Caretakers.
39.	Clarity of options and pathways as well as appropriate housing for adults with disabilities
40.	communication
41.	Communication with various stakeholders (who is who and what their role is). Less "we'll get to you when we can, but your input is required immediately." No more, "my annual report is due in 48 hrs."
42.	Community

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
43.	Companionship, someone to look after him
44.	Competent and reliable case management and supported living staff to help Rick remain in his own apartment.
45.	Complicated systems of support/care/benefits being simplified
46.	Connect him to services at a young age instead of taking care of everything because I could afford to do so.
47.	Continue a school program
48.	Continue the CDC+ program
49.	Don't know
50.	Easier access to funding for services
51.	Easier access to info on group homes or what is available for adult children who need help after their parents are gone.
52.	Easier access to more participating providers and specialists familiar with this population who accept Medicaid
53.	Easier way to find services
54.	education to the direct care staff on aging and DD
55.	Eliminate aggressive behavior
56.	Eliminate sending my adult to day programs where a meaningful day is subjective and staff is as consistent as a revolving door
57.	Everything. Activities for him, a center where he can get therapies and socialize, like a PPEC but for young adults.
58.	Extend / find opportunities for those that age out of school and transition.
59.	Fair wages to attract qualified Personal Care and Supported Living Staff/Employees.
60.	Family
61.	Find assistance which can be counted on if I am unable at some point to provide for her, who will enlist professionals if needed.
62.	Find help for a few hours per week locally
63.	Find my son a job, or hobby.
64.	FINDING SAFE QUALIFIED CARE GIVERS
65.	Finding someone who could give me guidance, or help just "punch out" things mentioned in prior question so I could get them "off my plate" so I could catch my breath & regain my health/joy.
66.	Flexibility to choose caregivers
67.	Found adequate care for him closer to home. Shaun needs intensive behavioral and medical care and no good services available in our area!
68.	Friends sometimes you feel alienated outside activities which are local
69.	Getting paid.
70.	Give more flexibility on how waiver money is spent
71.	Have a list to help determine where to get help

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
72.	Have a one stop local office the person I care for can depend on for assistance
73.	Have access to support services
74.	Have assistance!
75.	Have assistant more to help with her
76.	Have better access to services More continuous care
77.	Have better pay for APD's Direct Service Providers (group home staff) so the staff openings can be filled and so that staff will want to stay. New staff all the time is not good for a person with ID/D
78.	Have help at times
79.	Have more control over personalized services
80.	Have more help
81.	Have more help and options for quality care.
82.	Have more input in her care.
83.	Have more safe housing options for them.
84.	have respite care available
85.	Have the APD med waiver support coordinator do their jobs correctly. Stop privatizing. They have zero supervisor to be accountable. Pay rate to be increased for providers that come into the home.
86.	Having a day program in Titusville. I cannot work anymore now that she has aged out of school. Because of seizures she cannot ride the scat bus to BAC in Rockledge as aides are not allowed.
87.	Having access to more benefits and resources
88.	Having additional connections
89.	Having better information
90.	Having help come to our home
91.	Having local doctor's and specialist that know how to care for someone with Down Syndrome
92.	Having respite care to allow for caregivers to care for themselves too.
93.	Having time away from me where she feels included.
94.	Help
95.	Help from an HHA, companion for my son so he can go out in the community
96.	Help from someone who truly understands
97.	Help to qualify for help
98.	Help with loneliness for this person
99.	Help with household maintenance
100.	Help with placement
101.	her disability isn't developmental
102.	Him outliving me
103.	Home visiting providers for paperwork and therapy weekly. Online social work and psych for meds visits.
104.	House needs more physical accommodations

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
105.	Housing opportunities such as independent or assisted living.
106.	I do not know. I have to give it more thought.
107.	I don't know i have been doing this for 32 years
108.	I don't know
109.	I don't know
110.	I don't think I would change anything. I worked with a group home and I never had any problems with the system. We always worked well together.
111.	I feel like we have had to hunt down services, no coordination at all
112.	I guess we have to say it again as we do over and over and over and over - there are no services or quality help for anyone over 22
113.	I have someone to care for my son.
114.	I need a network of support from APD. Not just case manager
115.	I need a place or person with the knowledge to help me obtain the services that I will need.
116.	I wish I could be more tolerant, I am constantly after him for his loud speaking, his eating habit, etc
117.	I would have befriended more people who could take care of her when I die.
118.	I would have bought a home, and had it put into a trust that would not have been able to be taken away from him.
119.	I would have more respite time.
120.	I would have someone come in for respite.
121.	I would like more help from professionals, a team or classes to guide me during this time.
122.	I would like to know better how to manage his behavioral changes related to his disabilities
123.	I would love to have peace of mind that my adult son will live in a safe and user-friendly environment when I am no longer around.
124.	I would try to be more educated and get all the information on services available for my daughter
125.	I would wish for both of us to live independent lives.
126.	I wouldn't be a widow! Seriously, having someone else to confide in, consider and discuss options with, to help look for resources, would be an immense relief.
127.	I wouldn't worry about paying for an assisted living facility if my relative lives more than 5-6 more years.
128.	I'd have my bathroom made to accommodate a handicapped person. Small bathrooms don't work well with disabled person bathing.
129.	I'd make myself younger and healthier
130.	If I could change anything it would be knowing more resources to have been able to give her a more fighting chance at learning when she was younger
131.	I'm really not sure
132.	Improve the red tape of Social Security / SSI
133.	improved financial assistance. Money to enable home improvements and outside the home activities.
134.	In home services to remain in home of our choice.
135.	Inclusion programs and more community and natural supports

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
136.	Increase in Personal Supports hours
137.	Increase respite time.
138.	Increased funding and training to make finding quality caregivers a reality.
139.	Job coach services for our son
140.	Keeping him active and healthy
141.	Know that if something happens to me he will be ok. What services will he get without me.
142.	Know where to look for competent, caring in home support people outside family and friends.
143.	Knowing about available resources
144.	Knowing that all which needs to be solved as time goes by, is taken care of and that always is going to be a person available to take care and assist my daughter.
145.	Knowing that his next caregiver will be patient and loving towards him and treat him with dignity
146.	Knowing that my son would be lovingly and properly cared for when I am no longer able to do this because of a physical limitation or even that I am no longer alive to care for him.
147.	Knowing that she would have a caregiver when I'm gone.
148.	Knowing that there is adequate and safe housing once I pass away.
149.	Law when it comes to developmental disabled people speaking for themselves when they do not know what they are saying or signing
150.	Less red tape
151.	Less red tape getting services approved.
152.	Less stress
153.	Less uncertainty about housing, funding and care
154.	Let others help me
155.	Levels of day programming funded by dd waiver
156.	lifting him is increasingly difficult. I would want more personal care to assist with showering.
157.	living good life
158.	Living wage for PCAs
159.	Make information easier to understand and be accessible.
160.	make sure she is safe in a nice assisted living facility
161.	Making available services easier to access, rather than having to jump through hoops and bureaucracy.
162.	Making him independent
163.	Med waiver. Still on wait list. Its been 15 years!!! No help...
164.	Medical needs
165.	Mental Health Counseling for all of us. Transportation for her
166.	Money to give my child what she needs.
167.	More access to available services for him.
168.	More activities, daily life skills.

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
169.	More activities
170.	More alert, trained staff to help with her care
171.	More and better supervised day programs
172.	More behavioral support
173.	More caregivers availability. More day centers
174.	MORE COMMUNITY INCLUSION PARKS FOR ONE THING
175.	More day programs
176.	more employment opportunities for them
177.	More family involvement
178.	More financial aid for her.
179.	More flexibility to do what we think is needed for our adult disabled child with the budget we have.
180.	More funding
181.	More help
182.	More help
183.	More help for people in my situation
184.	More help in caring for my child
185.	More inclusive program of adults with disabilities.
186.	More in-home service
187.	More open resources to assist and navigate system.
188.	More programs to help adults with disabilities.
189.	More respite care, more behavior specialist, more services available. More understanding folks, just more where there is none available right now. Florida is not restricted but there are no services
190.	More respite options including overnight
191.	more respite without having to fight APD to keep the services every year.
192.	More services
193.	More services and longer day program hours
194.	more services at home and in the Community
195.	More services to assist with care.
196.	More services to make me feel more comfortable with leaving him to be cared for by others. Level of care
197.	More support
198.	More support and more possible respite
199.	More support services, activities and finding friends for my son
200.	more time for myself and rest
201.	Much better PAY for the caregivers so they will stick around with their clients for longer time. I did have a caregiver that was with my daughter for almost 10 years when the waiver paid much more!
202.	my daughter with hfa to obtain medwaiver.

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
203.	My son does not currently have a community service provider, both his Support Coordinator and I are trying to find someone for him.
204.	Na
205.	need help so I can work and respite to get sleep. Awake 20 hours a day because he doesn't sleep
206.	No change; many years . . .
207.	no idea
208.	No Medwaiver waitlist
209.	None
210.	none
211.	Not have had children in the first place. Silly question for someone on the waiting list
212.	Not have to worry about our son so we can actually go out of town on vacation.
213.	Not having a "big brother" program in place
214.	Not sure
215.	not sure
216.	not sure
217.	not sure - just making sure that they have all of the needed help and services to lead an "as normal" as they can lifestyle
218.	Not sure yet
219.	Not to have to do paperwork every year for my son that should be known. He is 100 % total care for both medically and physically disabled. Unfortunately it will not change.
220.	nothing
221.	Nothing
222.	Nothing at this time
223.	Nothing right now
224.	Nothing. I love my son.
225.	Offer safe group homes.
226.	People doing their jobs
227.	Personal support & Companion services be combined into one service under APD.
228.	properly trained staff and available services
229.	Provide more individualized care from actual responsible, well trained, caring personnel
230.	Provide the budget to develop, hire and train the skilled workforce that will be responsible to deliver all critical services to the aging disabled population (including, but not limited, proper livin
231.	qualified experienced caregiver
232.	Quality of life
233.	quality of services
234.	Receive more services to help take care of my daughter.
235.	Researching programs that are available for him.

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
236.	Respite care
237.	Respite care... consistent staff that get to know my son well enough to care for him when I need a break, get sick etc.
238.	respite respite respite
239.	Right now our needs are being met through the CDC+ program.
240.	Right now, things are ok.
241.	safe reliable timely transportation
242.	same as above (Having a residential community with supported living services available for my adult son so that there are multiple opportunities for growth, social engagement and integration into the greater community in a safe enriched environment.)
243.	Services like a day program, ADT, buddy matching, social outings.
244.	Social programs for my daughter
245.	Social security
246.	Some activity
247.	Stop making it all so hard to receive services. It takes forever to get anything approved. Why make it all about what is best for everyone but the person who is doing the caregiving?
248.	Support
249.	Support and a break
250.	Support and better programs for our developmentally disabled family members.
251.	support services of any kind, and a way to take a break
252.	Supports to stay in his home
253.	That he would be able to go to school during the day so he could continue to learn and socialize with peers.
254.	That I would not have to fight for services we currently need now, nevermind as she ages. We pay for her speech therapy and psychiatry visits out of pocket as the waiver budget we receive is minimal.
255.	That she wouldn't have a disability
256.	That there is a program that pays that caregiver (even if the caregiver is a father or mother) so that they can stay caring for the person with a disability but at the same time have an income.
257.	That we could receive some sort of services.
258.	The ARC services and Medicaid programs are difficult to navigate. My son's assigned Social worker doesn't work with other areas of waiver program.
259.	the availability of help and services for her.
260.	The means and ability to set her up in independent living conditions that I could begin teaching her into her how to live on her own before I die
261.	The Medicaid benefits not offer comprehensive dental benefits, also not have to much providers that accept Medicaid and no personal support available.
262.	There are not enough well trained, educated people to give the intellectually disabled the opportunity to advance their abilities.
263.	There is a lack of reliable support personnel. Group homes and day programs for individuals with significant behavioral issues are hard to find.
264.	Time lost in non-sense fighting for services for him.

If you could change one thing to improve your experience as a caregiver caring for an aging person with a developmental disability, what would it be?	
265.	Time to care for myself
266.	To educate the community so they could have more opportunities to be employed in the community working alongside other employees without disabilities.
267.	To have more hours for our daughter and transportation for her to get out in the community more.
268.	To have more information about service providers available.
269.	To have more programs closer to home that would help with things for him to do that are fun, safe, constructive and interesting to him so he could be a positive, productive individual.
270.	To have more supports and financial independence to be able to comfortably afford all the services we both need that is free of bureaucracy.
271.	To have my adult mentally challenged child in a group home
272.	To have periodic respite care so that I could be away for few days without having to worry about my son's well being
273.	To have programs available for my son to participate so he is busy during the day and can feel he has purpose, and hopefully friends or acquaintances.
274.	To have some guidance for services
275.	To have son be able to be more able to be independent
276.	Train someone younger in the family to take over what I handle for the aging dd individual
277.	Transitional services aging out from high school to adult
278.	Transportation
279.	Transportation
280.	try a family member
281.	try to find someone with enough sense to understand what these people go thru without having to put up with selfish, inconsiderate people that only think of themselves. governors, senators,
282.	unknown
283.	unsure
284.	Waiver as a Federal program so we would not have to worry about insurance and tea party politicians controlling our lives; having to worry every year whether we will have services or not
285.	Waiver to be a Federal program not subject to the caprice and mindless cruelty of politicians at the state level so I would not have to worry about care for my son disappearing or being cut from year
286.	We are at this time good and can provide for our son. I had a stroke lucky I survived and recovered. His dad is 75. 66. He is 36 brain function of 2 yr for life.
287.	We need more options!
288.	we try to do all we can and give all we can to our son
289.	Well trained and Better paid respite providers. Day centers, work options for those midrange on the spectrum. My son likes to be active but needs Supervision.
290.	Would have had people start working with him sooner on being independent
291.	Would have worked harder to get services earlier

Question 21 Would you like to participate in these efforts moving forward?

307 out of 309 answered



Names, emails and phone numbers that were provided in response to Questions 22-24 are not included in this report.

Reports can be found online at:

English - <https://jjohnson3.typeform.com/report/uhYxMLfn/xgWwt8yqNzqStpQx>

Spanish* - <https://jjohnson3.typeform.com/report/hOVcYU8G/fEbB2YSTKVMQ7Xb9>

Google Spreadsheet can be found at:

<https://docs.google.com/spreadsheets/d/1Dd5ILN4Pml-o5ez7iCMutmywOLksZbhdRATw57SzNKc/edit?usp=sharing>

*The Spanish response to the survey was translated and added to the results in this report.

Appendix J

Age Analysis Findings From Survey

Margaret Lynn Duggar & Associates was asked to conduct further analysis of the responses to the Aging Caregivers Survey that was sent out in March 2021. An analysis of the responses by age group was conducted and below is a summary of our findings.

Care Recipients 22 and below

Approximately 40% of the Respondents with care recipients in the age group of 22 and below reported receiving services for themselves or the individual with I/DD. For those receiving services, over half reported receiving case management or care coordination and 1/3 reported receiving respite care. With respect to future services needed, companion/aide and respite care were selected by 3/4 of the Respondents and 2/3 selected adult day care. A majority of the Respondents indicated that their greatest concerns and what they would change were availability and access to services and assistance for the individual with I/DD.

Care Recipients 23-30

According to the survey results, 59% of the Respondents with care recipients in the age group of 23-30 reported receiving services for themselves and 75% reported receiving services for the individual with I/DD. For those receiving services, approximately 3/4 reported receiving case management or care coordination and 1/3 reported receiving personal care attendant. With respect to future services needed, case management or care coordination was selected by 63% of the Respondents and 59% selected transportation. 75% of the Respondents indicated that their greatest concerns were about the care of the individual with I/DD when they were no longer able to care for them or are gone. 83% of Respondents reported that what they would change were availability and access to services for the individual with I/DD and assistance with navigating the system.

Care Recipients 31-39

Approximately 50% of the Respondents with care recipients in the age group of 31-39 reported receiving services for themselves and 72% reported receiving services for the individual with I/DD. For those receiving services, over 3/4 reported receiving case management or care coordination and 1/3 reported receiving adult day care. With respect to future services needed, case management or care coordination were selected by 2/3 of the Respondents and over half selected companion/aide. 63% of the Respondents indicated that their greatest concerns were about the care of the individual with I/DD when they were no longer able to care for them or are gone. 69% of Respondents reported that what they would change were improved access to services for the individual with I/DD, more variety of assistance offered, and increased knowledge and resources of what services and assistance are available.

Care Recipients 40-50

According to the survey results, 60% of the Respondents with care recipients in the age group of 40-50 reported receiving services for themselves and 73% reported receiving services for the individual with I/DD. For those receiving services, over 3/4 reported receiving case management or care coordination and 1/3 reported receiving personal care attendant. With respect to future services needed, case management or care coordination were selected by 80% of the Respondents and approximately 2/3 selected personal care attendant or companion/aide.

69% of the Respondents indicated that their greatest concerns were about the care of the individual with I/DD when they were no longer able to care for them or are gone. 45% of Respondents reported that what they would change were improved access to services for the individual with I/DD and themselves, increased funding for services and flexibility in spending.

Care Recipients 50-60

Approximately 60% of the Respondents with care recipients in the age group of 50-60 reported receiving services for themselves or the individual with I/DD. For those receiving services, approximately 90% reported receiving case management or care coordination and half reported receiving companion/aide. With respect to future services needed, case management or care coordination was selected by 3/4 of the Respondents and 2/3 selected companion/aide. 55% of the Respondents indicated that their greatest concerns were about the care of the individual with I/DD when they were no longer able to care for them or are gone. This was followed closely at 48% by concerns about qualified staff or suitable living arrangements for their loved ones. 64% of Respondents reported that what they would change were availability and access to services for the individual with I/DD and assistance with navigating the system.

Care Recipients 60-70+

Approximately 10% of the Respondents with care recipients in the age group of 60-70+ reported receiving services for themselves and 55% reported receiving services for the individual with I/DD. For those receiving services, approximately 73% reported receiving case management or care coordination and 1/3 reported receiving companion/aide or transportation. With respect to future services needed, case management or care coordination and transportation were selected by 55% of the Respondents and half selected companion/aide and counseling. 37% of the Respondents indicated that their greatest concerns were about the care of the individual with I/DD when they were no longer able to care for them or are gone and the availability and assistance with services. 21% of Respondents reported that what they would change were availability and access to services for the individual with I/DD and assistance with navigating the system. 80% of the Respondents in this age group identified as other family caregiver of an older person with a developmental disability

Appendix K

Research of Programs in Other States

Margaret Lynn Duggar & Associates was asked to research several initiatives in other states that could provide insight for the future of the Aging Caregivers Initiative. Below is a summary of our findings.

Hawaii Kupuna Caregivers Program

The [Kupuna Caregivers Program](#) (KCGP) is a pilot program launched in 2018 that is intended for employed Hawaiian residents who are also unpaid primary caregivers of a senior relative. This program helps to ease the financial burden of providing care for a loved one, while allowing the caregiver to continue their employment outside of the home. KCGP also helps to prevent the unnecessary institutionalization of seniors, saving the state money, as the cost of institutionalization is much greater than is support in the home and community. Via this program, up to \$350 / week may go towards the cost of long-term senior care and services, such as adult day care, in-home personal assistance, respite care, and more.

For the Kupuna Caregivers Program, there currently are no income or asset limits. However, there are other eligibility requirements for both the primary caregiver and the care recipient.

Primary Caregivers

Caregivers must provide care for an elderly individual who is a U.S. citizen or qualified alien who is at least 60 years of age. Furthermore, caregivers must work a minimum of 30 hours per week outside the home. (The caregiver may not be self-employed). The caregiver does not have to live with the care recipient.

Care Recipients

The Kupuna Caregivers program is an outgrowth of the State of Hawaii-funded [Kupuna Care program](#) (KC), which seeks to support community-living older adults with significant disabilities (near nursing-home level of care) who are not eligible for Medicaid but are at risk for both nursing home and Medicaid entry. It is intended to provide in-home services to impaired elders who fall in the "gap group." These are elders who do not qualify for other government programs and do not have private assistance to help. This normally includes those with financial resources not high enough to afford the high cost of private-pay services, but not low enough to qualify for regular Medicaid or have levels of care not high enough to qualify for LTC Medicaid (ICF/SNF levels of care).

To qualify, the elder must meet the following criteria:

1. Is 60 years of age or older;

2. Is a citizen of the United States or a qualified alien; provided that for the purposes of this paragraph, “qualified alien” means a lawfully admitted permanent resident under the Immigration and Nationality Act;
3. Is not covered by any comparable government service, private-pay service, or other home and community based care service, except for other Kupuna Care services;
4. Does not reside in a long-term facility, such as an intermediate care facility, assisted living facility, skilled nursing facility, hospital, foster family home, community care foster family home, adult residential care home, or expanded adult residential care home; and
5. Has impairments of at least: Two (2) activities of daily living (ADL); Two (2) instrumental activities of daily living (IADL); One (1) ADL and one (1) IADL; or substantive cognitive impairment that requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to self or others.
6. Having an unmet need of at least one or more ADLs, or one or more IADLs.

Activities of Daily Living (ADL): eating, bathing, toileting, mobility, dressing, and transferring.

Instrumental Activities of Daily Living (IADL): cooking, shopping, housework, use of public transportation, use of telephone, managing medications, and managing money.

KC services include: transportation, attendant care, case management, home-delivered meals, homemaker, adult day care, and personal care services.

Eligibility for home-delivered meals have additional requirements to the standard Kupuna Care criteria above, and impairments must consist of at least two (2) ADLs or substantive cognitive impairment. IADL impairments are not applicable to the eligibility of home-delivered meals. A person must also be homebound and meet at least one of the following criteria:

1. Lack the physical mobility and/or mental capacity necessary to shop for food, leave home for a congregate meal site, or to prepare adequate meals themselves, and have no one to assist;
2. Lack adequate cooking facilities, are unable to acquire them, and are unable to attend a congregate meal site;
3. OR are convalescing following discharge from a hospital or other convalescing facility and do not have help to prepare meals.

Priority for all services is given to older adults with greatest economic need, greatest social need, and/or at risk for institutional placement, with particular attention to those who are low-income, minority, with limited English proficiency, and/or residing in rural areas.

Eligible applicants are able to receive up to \$350/week to help cover the cost of senior care and services. These funds may be used for adult day care/adult day health, transportation assistance (including to and from adult day care/adult day health), respite care, home delivered meals, chore/homemaker services, and personal care assistance, such as bathing, grooming, dressing/undressing, mobility, etc.

Funds are not paid to the caregiver; rather they are paid directly to the service providers.

This program may have been modified since its launch in 2018

First Place-Phoenix

[First Place-Phoenix](#) offers supportive housing for adults with autism, Down syndrome and other neurodiversities and a residential transition program for adults with autism. Many adults with autism spectrum disorder (ASD), Down syndrome, traumatic brain injury and other neurodiverse abilities face unique challenges in daily living.

First Place–Phoenix is an innovative residential development that includes three major components: Apartments, Transition Academy and the Global Leadership Institute.

Apartments

Located in the heart of Phoenix, the 55-unit apartment property with a suite of supports and amenities maximizes independence, community integration, personal enrichment, and quality of life. Residents with autism, Down syndrome, traumatic brain injury and other different abilities enjoy the comforts of home in a unique environment specially designed with attention to sensitivity to light and sound. Multiuse spaces on each floor promote community involvement, interests, diversity, and friendships. It is transit oriented and within walking distance of light rail and public transportation.

Vocational staff at First Place work one-on-one with residents to help them chart a course for lasting employment by identifying their interests and specific skill sets.

First Place–Phoenix connects residents to jobs, internships, volunteer work and continuing education, as well as retail, restaurants, recreation, and arts and culture. Adults with autism, Down syndrome, traumatic brain injury and other neurodiversities live and learn among their neighbors within a compassionate and caring environment.

Transition Academy

The [First Place Transition Academy](#), operated by the Southwest Autism Research & Resource Center (SARRC), is a structured two-year program designed for adults with autism that helps build crucial independent living and career-readiness skills. First Place and SARRC have partnered to develop a state-of-the-art, educational transition program for 32 participants each year as they develop more independent-living skills within a

supportive, connected community. Participants take part in Learn4Independence®, a two-year curriculum of 32 semester-length courses (17 weeks each) taught on-site at GateWay Community College in Phoenix. During the Transition Academy's program, participants live in their own private bedroom in a four-bedroom suite on the first floor of First Place–Phoenix. They benefit from career services ranging from volunteer work and internships to employment.

The First Place Transition Academy accepts individuals who meet the following [criteria](#):

- Age 18 years or older and completion of high school or learning resource program.
- Diagnosis of autism spectrum disorder.
- Completion of basic self-care needs, including:
 - Can dress and bathe themselves without physical prompting
 - Can complete personal hygiene tasks without physical prompting
 - Can feed themselves without physical prompting
 - Has independent toilet skills and no nighttime enuresis
 - Can take and manage medication with oversight
- No current or chronic history of addiction or serious mental illness.
- Ability to participate and learn in a small-group setting.
- Ability to communicate wants, needs and discomfort/illness.
- No recent history (within the past 12 months) of severe aggression toward self, others or property, including self-injurious behaviors.
- Skills to safely function in their apartment and in the community without direct supervision during non-structured times.
- No interfering behaviors requiring intensive, one-on-one intervention.
- Expressed desire and willingness to participate in instruction, employment, and clinical programs, and to include parents/guardians in communication regarding progress.

[Learn4Independence](#) is a 32-course curriculum developed for adults with autism that focuses on skills to promote independent living and employment. Unique curriculum elements accommodate various types of learning differences and incorporate universally designed instruction adaptable to your community and cultural needs.

[Global Leadership Institute](#)

First Place [Global Leadership Institute](#) is empowered by a national faculty advancing the continued education and training of support specialists, professionals and physicians, and serving as a robust site for research and public-policy advancements. Developed by distinguished leaders in this highly specialized field, the Leadership Institute is focused on pressing concerns for accessibility to more community, housing, and independent living options for individuals with autism and other neurodiversities. As a resource to

organizations committed to serving special populations and their families, the Leadership Institute has developed a variety of [toolkits](#) addressing specific areas to meet an organization's needs throughout specific or all stages of the project.

Our Place Nashville

[Our Place Nashville](#) partners with non-profit organizations to provide brick-and-mortar housing called Friendship Houses throughout Nashville for adults with developmental disabilities. Our Place Nashville's Divinity Friendship Houses at Vanderbilt create an interdependent living environment comprised of residents with intellectual and/or developmental disabilities ("friends") and graduate students from Vanderbilt University, primarily from the Divinity School. A third Friendship House was opened in 2019 which integrates young adults with IDD, Vanderbilt Divinity School students and older adults into the Friendship House community.

Our Place Nashville empowers adults with developmental disabilities by providing homes that are affordable, work that is meaningful, and inclusive communities in which to live. 72 individuals in need of affordable housing are served in 4 Friendship Houses. This includes 28 friends, 24 graduate students, 6 family members and 14 older adults. For every two friends who reside at Friendship House, there are three neurotypical adults: graduate students and older adults.

Our Place Nashville helps their Friendship House resident friends find employment and volunteer opportunities that give them a sense of accomplishment, independence, and community.

Friendship Houses are not your typical house. Two of the current Friendship Houses are apartment buildings that house between 12 and 20 individuals (friends, students, or family members). Another is a three-story duplex that accommodates 20 people: eight friends, eight seniors and four students. Each side has 10 bedroom/bathroom suites with shared kitchens, living area and laundry facilities. Their fourth Friendship House which opened in the summer of 2020, is a one-story ranch house providing a shared living experience for 16 people: six friends and 10 seniors.

At the current time, they are unable to provide the supports needed by individuals with more pronounced challenges (e.g., needs help with personal hygiene) or who have anything but mild mental health problems. Applicants need to be able to live interdependently – with support but without 24/7 supervision. Some the resident friends were enrolled at Next Steps at Vanderbilt or Lipscomb's IDEAL program.

4 new Friendship House Communities are scheduled to open in 2021 and 2022.

Nashville's largest non-profit providers of affordable housing, Urban Housing Solutions (www.UrbanHousingSolutions.org) and Woodbine Community Organization

(www.WoodbineCommunity.org) are Our Place Nashville's primary partners. Average monthly rents vary from about \$325 to \$580 and go directly to the housing partner. Applicants have to prove their financial eligibility, and in many instances, parents have to co-sign the lease. Service fees for resident friends are \$600 a year.

Next Steps at Vanderbilt

[Next Steps at Vanderbilt](#) is a 4-year inclusive higher education program committed to providing students with intellectual disabilities an inclusive, transformational postsecondary education in academics, social and career development, and independent living, while honoring equality, compassion, and excellence in all endeavors.

It is a comprehensive transition program designed to serve students with intellectual disabilities. Although applicants may have other disability diagnoses (e.g., autism, functional delay), emphasis is on students who also have cognitive impairments.

They accept students who are between the ages of 18 and 26. Transfer students are eligible to enter through the age of 28.

They serve students with disabilities who have successfully completed high school, and have received a high school diploma (e.g., special education diploma, occupational diploma, standard diploma). Additional eligibility requirements can be found [here](#).

The [Individual Program of Study](#) is a unique and customized plan for achievement in academic areas, independent living skills, career development, and university life. While Next Steps students work towards completing an individual Program of Study, they must also complete the program to earn a Career and Community Studies certificate upon completion.

Next Steps at Vanderbilt's [Career Development Program](#) of study assists students in developing the skills, experiences and supports necessary for a successful transition into paid employment upon graduation.

Next Steps peer mentors, known as Ambassadors, are undergraduate and graduate students who establish one-on-one relationships with students enrolled through Next Steps. Types of mentoring support include:

- Lunch partners – focus on social skills and healthy eating goals.
- Workout partners – help to increase stamina and establish safe exercise habits.
- Academic tutors – assist students with academic work and encourage good study habits.
- Daily planners – focus on organizational skills and completion of Next Steps program requirements (e.g. scheduling, journal).

- Campus Life Ambassadors (CLA) – plan alongside students and then participate in campus life opportunities together (e.g. football game, service project).

Lipscomb University IDEAL Program (Nashville)

[IDEAL](#) is a unique two-year program created by Lipscomb's College of Education to offer a college experience for students with intellectual and/or developmental disabilities (ID/DD). The program is based on the Think College Standards and other successful postsecondary programs. It is designed to encourage and support these students as they experience college with their peers.

The ultimate goal of the Career Skills program is to equip students to obtain better employment options. Lipscomb has many community partners that provide a variety of internships and job training opportunities for IDEAL students. Students begin in their first semester with on-campus internships. These placements are sought once the career goals are identified for each student. The goal is to scaffold necessary skills so the student is always learning and practicing skills that will benefit them in their future job placement. Students are placed in off-campus internships in their second year of the program. The students' job interests and abilities are matched with available openings. Students complete at least four work experiences to include on their resumes upon completion of the program as a result of these on-campus and off-campus internships.

Students audit (or take for credit) two academic classes per semester based on their interests and career goals, such as art, theater, music, science, IT, nutrition, health, education, early childhood studies, and/or Bible.

Many students with ID/DD need assistance with independent living skills that will help them be better employees and give them the option to live independently. Each IDEAL student takes two classes per semester that teach these skills. Skills may be in the areas of technology, banking, cooking, cleaning, shopping, hygiene, social skills, self-awareness, safety, and self-advocacy. Students learn to make a resume, look for jobs, use public transportation, and manage their own time. The goal is that the students will be as independent as possible when they leave the program.

Peer Mentors are an essential component of the program. Lipscomb students serve as peer mentors to the students with ID/DD and accompany them to meals, chapel, and the gym. They also help them study and organize their course materials. Volunteers are matched based on expertise, desires, and their individual class schedules.

Ultimately, IDEAL helps to bridge the gap between high school and adulthood for every student who participates in the program. Being more prepared for adulthood greatly enhances the IDEAL students' quality of life.

Louisiana Elimination of Waiting List for those with Developmental Disabilities.

The [Louisiana Department of Health](#) received approval from the Center for Medicaid and Medicare Services (CMS) to combine each existing request for services registry (list) for individual waivers into a single request for services registry. In addition, the Department received approval to change how people receive waivers by offering the most appropriate waiver type based on a person's identified needs.

This moved Louisiana from a first come, first serve basis for community-based services or waiver services to a [Tiered Waiver](#). This means that individuals with a greater urgency of need will now be prioritized for receiving the most appropriate home and community-based services. The Department began a screening process to evaluate the needs of the more than 10,000 individuals who were on a waiting list for services.

The screening, using a nationally accepted best practice, considered what services and supports were already in place, whether or not the person was eligible for Medicaid, the severity or complexity of the person's disabilities, what additional supports may be needed and any changes in an individual's life or living situation.

Each case was given a Screening for Urgency of Need (SUN) Score to determine the urgency of need for waiver services. Five levels of need, or tiers, were created.

- 4-Emergent: Supports will be needed in the next 90 days. (7% of the individuals requiring services)
- 3-Urgent: Supports will be needed in the next 3-12 months. (8%)
- 2-Critical: Supports will be needed in the next 1-2 years. (22%)
- 1-Planning: Supports will be needed in the next 3-5 years. (23%)
- 0-Currently no unmet needs (40%)

Everyone in Tiers 3 and 4 will be offered the most appropriate services and supports. As of today, all of the people on this waiting list who have an urgent or emergent need for waiver services have received a waiver opportunity.

While the Department will continue to maintain a registry of individuals, today, the registry reflects that those with needs are receiving the services necessary to continue living in a home or community environment. The registry allows the Department to plan for and to be responsive to individuals if their needs change, becoming urgent or emergent.

The following [waiver services](#) are offered:

- **Children's Choice Waiver** offers supplemental support to children through age 18 who currently live at home with their families or with a foster family.
- **New Opportunities Waiver** offers people age 3 and older who otherwise would require the level of care of an Intermediate Care Facility for the Developmentally

Disabled (ICFs/DD) services that allow them to remain in their communities. Services are based on the need of the recipient and are developed using a person-centered process to formulate an individualized plan.

- **Residential Options Waiver** offers people of all ages services designed to support them to move from ICFs/DD and nursing facilities to community-based settings, and to serve as an alternative to institutionalization.
- **Supports Waiver** offers focused, individualized vocational services to people age 18 and older who otherwise would require the level of care of an Intermediate Care Facility for the Developmentally Disabled (ICFs/DD).

