SATISFACTION GUARANTEED? IMPROVING DEVELOPMENTAL DISABILITY FAMILY SUPPORTS PROGRAMS: A PHENOMENOLOGICAL MIXED METHOD STUDY

Dissertation in Practice
Submitted to
The School of Education and Health Sciences of the
UNIVERSITY OF DAYTON

In Partial Fulfillment of the Requirements for
The Degree of
Doctor of Education

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Dayton, Ohio
August 2023

SATISFACTION GUARANTEED? A DISSERTATION IN IMPROVING DEVELOPMENTAL DISABILITY FAMILY SUPPORTS PROGRAMS

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EXECUTIVE SUMMARY

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People with developmental disabilities (DD) overwhelmingly rely on family caregivers to provide the support they need at home and in the community, often because of limited funding, long waiting lists for paid services, and more recently a dangerous shortage of paid caregivers. Family caregivers experience physical, social, and psychological demands of the extended caregiving they provide and have poorer health outcomes, negative impacts on their financial well-being, and higher incidence of stress and depression than non-caregivers.

Family Supports (FS) programs provide services and other resources designed to help individuals with disabilities remain living in their family homes (Freedman et al., 2000; Heller et. al., 1999). These programs often offer flexible but limited funding for services and are consumer-directed in that individuals with DD and their families can decide which services they want to access, and in which amounts within their funding allowance. Given the significant demands on family caregivers over the lifetime of a person with a developmental disability, FS programs must be considered a viable option to provide at least some support to people who may be waiting for other funding options. In some states, FS programs may not be available or may be underutilized.

This study was designed to understand the factors that influence people to utilize (or not utilize) a FS program, and to measure how useful FS program services are to people with DD and their families. Research questions also asked if there were relationships between satisfaction and demographic characteristics or specific need factors of people served. Using both a phenomenological approach and Andersen's behavioral model (1995) as a framework, the study employed an explanatory sequential practical action research model, consisting of a quantitative survey followed by qualitative interviews to expand on the quantitative findings. Participants included family caregivers of individuals with DD currently and previously enrolled in a FS program administered by one agency in a large metropolitan area in a Midwestern state in the U.S.

Both participants enrolled in the program and those previously enrolled gave similar ratings (helpful or very helpful) to program services, were satisfied or very satisfied with the FS program, and willing to recommend it to others. Participants did give overall higher ratings of service usefulness than non-participants, which may explain why non-participants are no longer enrolled in the program. Program participants specifically rated the services of camp and incontinence supplies as more useful than non-participants, which may have been related to the timing of the research post-COVID pandemic when these surveys were in high demand and low supply. Participants also provided helpful suggestions for FS program improvement to improve ease of access to services, allow for greater self-direction, and include ongoing feedback of caregivers and participants in future FS program decisions.

Dedicated to my three daughters. You are brave, smart, and kind, and each of you makes this world a better place. I am forever grateful to be your mom, and I can’t wait to see where your lives take you. When things get difficult, remember: Nevertheless, she persisted. You will too, and I will be right here to help.

To my family and friends, especially my husband, who supported me through this process and never hesitated to pick up the slack when I needed to spend hours on end writing or had class. Your encouragement and support helped me tremendously. Thanks for rescheduling things, understanding when it took me too long to respond, and for always reminding me that “I like school” when I would get stuck. You’re right, but I think after this I’m ready for a break…at least for a little while.

To Mom, Dad, and Gram: Oh how I wish you were here to celebrate with me!

ACKNOWLEDGEMENTS

I would like to extend a special thank you to Dr. Davin Carr-Chellman and Dr. Aryn Baxter, each of whom served as my DiP advisor during some portion of this adventure. You provided me with expert guidance and feedback throughout the course of this process. Dr. Carr-Chellman, your confidence in me was exactly what I needed when things were hectic. Somehow you always knew I would get my writing done even when I was not as sure. I also appreciate Lori Stanfa, for serving on my dissertation committee and for always sharing your tremendous knowledge of the DD field and supporting me personally and professionally. You have truly made the world a better place for people with developmental disabilities. And finally, to Dr. Meredith Wronowski, I am thankful for your kindness and patience with my many questions about quantitative analysis.

My colleagues at DDS have been overwhelmingly supportive of my research, helping me develop surveys, getting surveys to the right people, and then implementing the changes to improve the program. Thank you to the agency CEO, who permitted me to do this research on the FS program, and for helping me become the leader I am today.

Finally, I am extremely grateful to those current and past participants and caregivers of the FS program who took the time to return surveys and/or talk to me about their experiences. Your willingness to trust me enough to share the details of your lives with me helped me see the FS program and the services DDS provides in a completely different way. Your candor and vulnerability showed your genuine dedication to improving services for people with DD and I loved hearing about the “superpowers” of the people you support. Without you, this research would not have been possible. A sincere thank you to each of you.

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LIST OF ABBREVIATIONS AND NOTATIONS

ANOVA	Analyses of Variance
ANCOVA	Analyses of Covariance
DD	Developmental Disability/Developmental Disabilities
DDS	Developmental Disability Services, Inc. (Anonymized)
FS	Family Supports
HCBS	Home and Community Based Waiver Services
IDD	Intellectual and Developmental Disabilities

CHAPTER ONE

PROBLEM OF PRACTICE

In 2016, approximately 7.3 million people in the United States were diagnosed with an intellectual or developmental disability, with an estimated 71% of those people living with a family caregiver (Anderson et al., 2018; Larson et al., 2018). Families who provide housing and care for these individuals provide tremendous support to the developmental disabilities (DD) system overall. Research repeatedly shows that people who participate in consumer-directed programs, which recognize individuals with disabilities as experts regarding their needs and provide them with resources to obtain services they determine will be most helpful, experience several benefits and report high levels of satisfaction (Kosciulek, 1999; Swaine et al., 2016; Wiener et al., 2007). This study will explore the reasons why individuals and families utilize consumer- and family-directed support programs and the barriers they experience related to these programs.

The Problem of Practice

People with intellectual and developmental disabilities are significantly underserved, with thousands of people on waiting lists throughout the United States waiting for services (Burke & Heller, 2017; Prouty et al., 2005). Family Supports (FS) programs provide services and other resources designed to help individuals with disabilities remain living in their family homes (Freedman et al., 2000; Heller et. al., 1999). These programs often offer flexible but limited funding for services and are consumer-directed in that individuals with DD and their families can decide which services they want to access and in which amounts within their funding allowance. Given the significant demands on family caregivers over the lifetime of a person with a developmental disability, FS programs must be considered a viable option to provide at least some support to people who may be waiting for other funding options. In some states, FS programs may not be available or may be underutilized.

Developmental Disability Services (pseudonym), a government agency in the midwestern United States, administers a FS program that provides flexible but limited funding for services for individuals with developmental disabilities that live with their family. Developmental Disability Services (DDS) significantly adjusted the enrollment criteria and application process for their FS program in 2020 to increase the number of families who could access these supports. The result was that 95% of people eligible for the FS program enrolled in it. However, there were still a few hundred people who were eligible but did not access the program, leaving a number of individuals with DD and their families without access to these consumer-directed services.

Justification of the Problem

The 2021-2022 strategic plan for DDS outlines several goal areas for the agency including “people have access to needed supports” and “people receive person-centered, quality supports” (Developmental Disability Services, n.d.). In line with those strategic goal areas, one objective for 2021 was to increase the number of people enrolled in the FS program. While the agency was successful in this objective and increased the number of people enrolled in the FS program by one thousand over a two-year period, as of April 2022, there were still 615 people who were eligible for services but did not access the program. In addition, of those who did enroll in the program, 85% of them did not utilize their entire annual budget to access services available to them. In fact, 2021 FS program data showed that only 37% of participants used at least 95% of their allowance, and a full 34% did not utilize any of their funding allowance for the year.

Understanding the characteristics of individuals and families who do and do not access the agency’s FS program and aspects of the program that are most useful to them can be utilized to improve DDS’s FS program. This information may also benefit the individuals who do not access DDS services even though they are eligible for them by creating a program that is more useful for supporting their needs. Specifically, these findings could be beneficial in the areas of program recruitment and services offered. In addition, results from this study could persuade other agencies to create or expand FS programs and could assist advocates with legislative efforts to increase financial commitment to these programs in many states.

Deficiencies in the Organizational Knowledge Record

Although over 95,000 people receive DD services in the state where DDS is located, fewer than half of them are currently enrolled on Medicaid Home and Community Based Waivers, which typically fund comprehensive long-term services (State Department of DD Services, n.d.). However, there is no comprehensive statewide data on FS programs in the U.S., or in most individual states, including the one where DDS is located. Information from this study could be beneficial to almost one hundred other agencies similar to DDS in this state alone. Most research regarding FS programs has explored the benefits and evolution of such programs. There is less research regarding factors which influence family participation in FS programs.

Audience

DD professionals in the Midwest and throughout the United States as well as advocates and family members of individuals with DD are the intended audience for this research study.

Overview of Theoretical Framework/Methods/Research question(s)

This study used two theoretical frameworks. First was a phenomenological conceptual framework. Phenomenology is a qualitative research approach that focuses on the perception or understanding of a lived experience. Essentially, phenomenologists are interested in how a person thinks about something (Willis, 2007). Often phenomenologists are interested in how a group of people perceive a shared experience. This research approach falls in the interpretive or constructivist paradigm, which seeks to understand phenomenon by interpreting the meaning of interactions, events, and objects (Hesse-Biber, 2017). Reality exists as it is experienced by people and is influenced by their beliefs and values (Walliman, 2011). This research study was interested in the perception of families who receive FS program services from Developmental Disabilities Services, and why they believe they are or are not valuable.

Additionally, this research study employed an explanatory sequential action research model. Also called a two-phase model, this approach involves first collecting quantitative data and then collecting qualitative data that helps elaborate on the quantitative findings. Andersen’s model (1995) was designed to look at access to and utilization of services, exploring predisposing factors (including demographics of the person), enabling factors (those that support and encourage access to services) and need factors.

This study addressed the following research questions:

- What factors influence families to utilize (or not utilize) FS programs?
    - Is there a relationship between demographic factors (racial, ethnic, age, or gender) or need characteristics (mobility, communication, or behavioral/mental health challenges) and whether or not people would recommend the DDS FS program and if so what is it?
    - Is there a difference in perception of service usefulness between different demographic groups?
    - Is there a relationship between ratings of service usefulness among people with mobility, communication, and behavioral or mental health challenges or their caregivers?
- How are services available through the FS program useful to individuals with DD and families?

The study included both a quantitative survey and a qualitative interview component. Using a sequential explanatory mixed method approach allowed for maximum participation and for in-depth insight into why individuals may not access or utilize the DDS FS program.

The participants in this study were family caregivers of children and adults with developmental disabilities who enrolled in the Developmental Disabilities Services FS program in 2022 (participants), and those who were enrolled in the program in 2020 or 2021 but did not reapply in 2022 (non-participants). It was anticipated that the response rate for the non-participant group might be minimal, as they are families who did not re-enroll in the program from one year to the next. As such, a combination of data from both non-participants and participants was utilized to extrapolate the possible reasons that non-participants left the program.

Limitations

This action research study was limited in that the people included in the study were served by one type of program in one urban area in the Midwest United States. As such, any findings cannot be universally applied to other types of DD programs or other states or countries, although findings may provide justification for further research. In addition, this study was limited by the fact that it relied on people including those that did not apply for the FS program to respond to surveys about why they did not reapply. The study was partially limited by response rates (7%) of non-participants.

Review of Related Literature

Supports to individuals with intellectual and developmental disabilities in the United States have a long and complex history, complete with a service model that continues to evolve and improve. Although Family Support programs are not new, their potential as an option that provides self-direction opportunities for individuals served and relief for caregivers demands that they should be a priority for additional consideration. This review highlights important elements that must be considered in designing or administering Family Support programs and describes a possible model for evaluating their utilization (Andersen's Behavioral model).

Definitions and Prevalence of Intellectual and Developmental Disabilities

According to the federal *Developmental Disabilities Assistance and Bill of Rights Act of 2000* (DD Act), a developmental disability is a "severe, chronic disability that is attributable to a mental or physical impairment, is evident prior to age 22, and results in substantial functional limitations in three or more areas of major life activity" (42 U.S.C. §15001 et seq.). These life activities include self-care, communication, learning, mobility, self-direction, independent living, and economic self-sufficiency. While any program that uses federal DD funds must utilize that definition, many states develop their own definition of DD for programs that are state funded, with over half of states requiring specific medical diagnoses to be eligible for programs (Williams et al., 2017).

Intellectual Disability (ID) is a term not defined in federal statute. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines ID as a "disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18" (Anderson et al., 2019, p. 422). Both the U.S. Supreme Court and the President's Committee for People With Intellectual Disability recognize the AAIDD definition. Intellectual functioning is measured by standardized intelligence tests that assess general mental ability including problem solving, abstract thinking, planning, reasoning, learning, and comprehension of complex ideas (Schalock et al., 2010). A significant limitation in intellectual functioning is operationally defined as an IQ score that is two standard deviations below the mean. Adaptive behavior related to the definition of intellectual disability refers to a variety of social, practical and conceptual skills that people perform in their everyday routines (Schalock et al., 2010). Among many others, they include interpersonal skills such as social responsibility and social problem solving (social skills), activities of daily living, occupational skills, safety and use of money (practical skills) and language, reading and writing, and number concepts (conceptual skills) (Schalock et al., 2010).

Although there are overlaps in the definitions of DD and ID, there are differences that are important to note. Not everyone with a developmental disability has an intellectual disability. According to the definition provided by the DD Act, an individual with Cerebral Palsy or Epilepsy with average or above average intelligence may qualify for DD services. Similarly, individuals who meet the criteria for an ID diagnosis may not have substantial functional limitations in three or more of the DD act areas (Havercamp et al., 2019).

It is challenging to obtain accurate, updated population data regarding the number of individuals with intellectual and developmental disabilities in the United States as there are few systemic efforts to study prevalence in the U.S. (Anderson et al., 2013; Anderson et. al., 2019; Emerson et al., 2013; Havercamp et al., 2019; Krahn et. al, 2010). Anderson (2019) outlined several prevalence studies used in the U.S., each with different approaches and weaknesses. Particularly relevant to this research study is the issue of definitions of developmental disability versus intellectual disability, as many surveillance tools either include only one definition or the other or do not distinguish between the two in any way. For the purposes of this literature review, research relating to individuals with both intellectual and developmental disabilities (IDD) is included. Anderson and colleagues (2019) found that the data vary widely, from prevalence estimates of people of all ages with ID of 7.8 per 1,000 to 137 per 1,000, and for people of all ages with DD estimates ranging from 11.3 per 1,000 to 41.0 per 1,000.

The most widely accepted estimates are that 2% of the U.S. population, or approximately seven million people, have an intellectual or developmental disability (Larson et al., 2001). Although relatively small, this population are recipients of significant public and private expenditures, including institutional and home and community-based services (HCBS). Individuals with intellectual and developmental disabilities accounted for 30% of all Medicaid expenditures in 2016, with 7% of all Medicaid-funded long term services and supports going to people with IDD (Eiken et al., 2017).

The Evolution of IDD Services and HCBS Waivers

Throughout most of the 19th Century, hundreds of thousands of individuals with intellectual and developmental disabilities were placed in institutions that arose to house people previously served in almshouses, poor houses, or hospitals (Trent, 2016). Often called mental asylums or homes for the feeble minded, these facilities isolated residents and "protected" mainstream society from individuals with disabilities and mental illness. It was widely believed that it was in the best interest of individuals with disabilities and their families that these individuals be placed in different residences outside the family home. As such, families were often encouraged and agreed to place their children with disabilities in institutions so that they could receive what they believed would be proper care (Burke et al., 2018). However, many of these facilities provided custodial care at best and at worst many residents suffered abuse and neglect (Burke et al., 2018; Trent, 2016).

In the late 1960s and early 1970s, talk of deinstitutionalization began in the United States. Fueled by pressure from parent groups who had started to advocate for the creation of special schools for disabled children, and in combination with national outrage after conditions at many institutions came to light, states began to work on plans to replace institutions in favor of services in the community (Burke et al., 2018; Trent, 2017). In 1965, the Medicaid program was created, establishing a state-federal government entitlement program which provided a legal right to services for those who meet eligibility criteria (Braddock et al., 2005). In 1971, the ICF/MR (intermediate care facility for the mentally retarded) program was created. Now known as the ICF/ID (intermediate care facility for individuals with intellectual disabilities) program, it was designed as an optional residential benefit regulated by states, paid for by Medicaid, and designed to support individuals with IDD who required active treatment (Burke et al., 2018). These facilities had to meet conditions of participation that focused on client protections and rights, active treatment, and physical environment, and were generally smaller than and considered to be more community focused than large state institutions of the past. However, eligible individuals with disabilities needing residential services still had to live in a congregate, institutional setting by choosing either a skilled nursing facility or an ICF/ID.

In 1981, the Medicaid Home and Community Based (HCBS) Waiver program was created. As such, people with disabilities had an alternative to institutional care and were able to choose to receive services in the community. Over the 40 years that has followed, the system worked to rebalance from being heavily focused on publicly operated institutions to community based services. Largely due to advocacy and class action litigation, access to HCBS waivers has increased while the census of IDD institutions decreased by almost 90% as of FY 2015 (Braddock et al., 2017). In FY 2015, there were 115 waiver programs in 46 states and the District of Columbia that provided services to 741, 285 people with IDD (Braddock et al., 2017; Friedman, 2017).

Some individuals enrolled on HCBS waivers live in licensed group homes with other individuals with disabilities and receive services from certified providers in areas of their lives in which they need support, such as activities of daily living, shopping, banking, healthcare, accessing the community, and finding or maintaining employment (Developmental Disabilities Services website). Others live in homes they rent or own, with or without roommates, and receive support from provider staff they choose (Developmental Disabilities Services website). Other individuals live with their families and have paid providers deliver services as needed in the family home (Developmental Disabilities Services website). Assistive technology, home modifications, and adaptive equipment as service options added to various states' HCBS waiver plans also expand living options in the community for individuals with disabilities. Overall, studies have shown that community-based services provide numerous benefits to individuals with disabilities compared to institutional care, and a significant factor in the ability to provide those services has been HCBS waivers (Burke et al., 2018; Mansell, 2006).

The dramatic growth in HCBS waivers for individuals with IDD has been beneficial in improving the outcomes for individuals as compared to institutionalization, as well as increasing the number of choices available to individuals and their families regarding where they receive services and who provides them. Choice in service location and service provider is an important tenet of the HCBS waiver program. However, there are many people still on waiting lists for HCBS and/or residential services in many states, with some estimates ranging from 83,101 in 1997 to 76,677 in 2013 (Burke & Heller, 2017; Heller et al., 1999; Prouty et al., 2005). Because many individuals with IDD enrolled on HCBS waivers receive services throughout their lifespan, states must account for the long-term financial commitment for each waiver they allocate to someone. As such, states maintain waiting lists when they do not have sufficient resources to enroll everyone on a HCBS waiver that needs one. Simply stated, the IDD system overall lacks sufficient financial resources to provide care for every individual with IDD who needs it.

IDD System Challenges

The financial challenges the IDD system faces cannot be understated. However, perhaps just as concerning to individuals and families is the significant workforce shortage impacting the IDD system. Recruitment and retention of direct care staff to care for individuals with intellectual and developmental disabilities have been a challenge for more than 25 years (Jaskulski & Ebenstein, 1996; Hewitt & O'Neill, 1998). However, in recent years this workforce shortage has developed into nothing short of a crisis.

In 2020, there were approximately 4.6 million direct care worker jobs in the United States. People in these positions support individuals with disabilities or older adults with activities of daily living, and are employed in a variety of different settings from nursing homes and assisted living facilities to residential homes (PHI National, n.d.). In the IDD field these workers are typically referred to as "direct support professionals." While direct care is already the largest single occupation in the country, it is estimated that in the next 10 years an additional one million new jobs will be needed to support the demand of an aging U.S. population (PHI National, n.d.).

Hiring direct care workers is difficult because the positions often come with poverty-level wages, economic instability of part-time schedules, and limited or nonexistent medical benefits and paid time off. It is estimated that over 40% of direct care workers live in poverty and access some form of public assistance (PHI National, n.d.). In the IDD field, it is even more difficult to find direct support professionals who are willing to provide care at such low pay when the job may come with the additional challenges of working with individuals who struggle to communicate their needs in traditional ways or may need very specialized supports.

The COVID-19 pandemic had a significant impact on the direct care workforce. While many industries experienced labor shortages and new levels of employee turnover, DD service providers reported unprecedented levels of staffing shortages (State Department of DD Services, n.d.). Poorly paid direct support professionals were expected to work throughout the pandemic, often with individuals who had tested positive for COVID-19, and under circumstances when personal protective equipment was in short supply or not available (PHI National, n.d.). As the pandemic wore on, many direct support professionals left the DD field and direct care altogether in search of other opportunities in a job market that had many higher-paid opportunities.

Many states throughout the U.S. are reporting staffing shortages that are directly impacting the lives of individuals with developmental disabilities. DD service providers have made difficult decisions to close homes, forcing people to relocate and allowing them to better use the staff they have available (Midwest Agency, n.d.; Peterson, 2019; State Department of DD Services, n.d.). Others have been able to continue supporting people they were already working with, but have not been able to serve any new individuals or families no matter how much they might need help (Institute on Community Integration, 2018; Peterson, 2019). Some states are waiving requirements regarding who can work with individuals with disabilities to try to provide some relief, and many states have enacted emergency payments to providers to allow for increased wages during the pandemic (Bishop, 2021; State Department of DD Services, n.d.). There is consensus throughout the field that these measures are necessary, but not enough to address the long-term issue of insufficient staffing to support people with intellectual and developmental disabilities in the community (Institute on Community Integration, 2018; Peterson, 2019). Until this is addressed, families will remain an absolutely critical part of any IDD service system.

The Role of Family in Supporting People with IDD

While hundreds of thousands of individuals with IDD live in the community on their own or with paid supports, families remain the single most vital support to individuals with IDD. Approximately 71% of individuals with IDD live at home; 25% of them are cared for by a caregiver over age 60 (Factor et al., 2012). Adults with IDD remain living with family far longer than their typical peers, with 60% of these adults living with family (Braddock et al., 2013). Some adults with IDD will remain with family for their entire lives. Parents and family members play a critical role in providing care to individuals with disabilities and as such, offer tremendous support to the IDD system as a whole. The numbers of individuals needing and receiving care become even more relevant as the population ages. While in 2015, it was estimated that 641,000 people with IDD were over age 60, that number is expected to double to more than 1.2 million people with IDD who may need care by 2020 (Factor et al., 2012).

Given the important contributions parents and family members provide to the sustainability of the overall disabilities system, it is important to understand the unique physical, social, and psychological demands of the extended caregiving they provide. Parents of children with IDD experience poorer physical and mental health outcomes at early old age (i.e. their 60's) compared to their peers without children without IDD, especially when their adult children live with them (Burke et al., 2018). Many researchers have found increases in stress, depression, and psychiatric problems and an overall negative impact on the financial well-being of family caregivers of adults with DD (Burke et al., 2018; Heller et al., 2015). Siblings of individuals with IDD anticipate needing to fulfill caregiving responsibilities when their parents are unable to do so, and report needing support and information about the DD system (Burke et al., 2018).

A review of interventions available to family caregivers in the DD and aging populations found a number of different programs available to caregivers. Programs varied, with some arranging for care coordination, providing home and financial support, education and training, or psychosocial support and therapy. All interventions were associated with positive outcomes for caregivers (Heller et al., 2015). As families continue to care for individuals with disabilities, and both groups live longer, it is critical that the IDD system find ways to support these family units. If nothing else, the economic value of this type of support, estimated at over $257 billion a year, must be considered as a reason to support family caregivers (Arno et al., 1999; Arno, 2002).

Person-directed Supports

Another significant evolution of service-delivery for individuals with IDD has been the widespread acceptance of person-directed support models. Also called consumer-direction or person-centered services, these models recognize the ability and rights of individuals to "assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive" (National Institute on Consumer-Directed Long-Term Services, 1996, p.4).

Powers and colleagues (2006) point out that the increasing reliance on these models is in part reflective of a societal shift acknowledging the capabilities, autonomy, and rights of individuals with disabilities. Additionally, there is a growing body of evidence regarding the positive benefits of person-directed supports for individuals with disabilities, including increased perception of control, quality of life, and overall satisfaction.

While there are several models of person-directed services, most include several important elements (Powers et al., 2006):

- the authority of the service user/person with a disability
- individualized planning and funding of service plans
- ability of the individual receiving services to select, train, and supervise providers
- flexible benefits or services
- service quality as defined and monitored by the person served
- limited oversight by medical providers

Family Support Programs

FS programs provide services and other resources designed to help individuals with disabilities remain living in their family homes (Freedman & Boyer, 2000; Heller, et. al., 1999). These programs aim to avoid unnecessary institutionalization or out of home placements and support the capacity of families to provide care (Agosta & Bradley, 1985; Freedman & Boyer, 2000). Services available through FS programs may include respite, personal care, recreational and camp services, therapies, transportation, home modifications, assistive technology, family education and training, and family counseling (Freedman & Boyer, 2000; Heller & Caldwell, 2005). FS programs are typically designed to be person-directed, whether through individualized budgets or cash subsidies, and are often fairly low cost in nature overall especially compared to HCBS services. These programs often allow for individuals to choose their caregivers, permitting many of them to hire family members and strengthen the networks of informal support they already have in place (Caldwell & Heller, 2007).

There is growing evidence that FS Programs offer significant benefits to individuals and family caregivers. Caldwell & Heller (2007) found that families enrolled in programs with individualized budgets had decreased unmet service needs, higher service satisfaction, increased community participation of individuals with disabilities, and decreased caregiver burden over time. Other studies showed fewer out of pocket disability expenses, decreased need for out of home placement, greater access to healthcare, engagement in more social activities, greater leisure satisfaction, better mental health for lower income caregivers and improved coping and attention to their children's needs (Agosta & Melda, 1995; Allard et al., 1993; Caldwell, 2006; Zimmerman, 1984). Other studies suggest additional impact included an increase in employment rates for mothers of individuals with disabilities (Caldwell & Heller, 2003). Finally, there is evidence that these programs are strongly preferred by individuals with IDD (Caldwell 2006; Caldwell & Heller, 2007; Neely-Barnes et al., 2008).

Despite the many benefits of FS programs, not all states utilize this option to support individuals and family caregivers. The majority of FS programs originate as state-funded programs and as the number of people on waiting lists for HCBS waiver services continues to grow, states must decide where to commit their often-limited dollars. In 2003, it was estimated that less than 4% of funding in the IDD service system was allocated to family support (Parish et al., 2003). Some states have converted FS programs to Medicaid funding, but overall, there is reluctance to do so primarily because of the loss of flexibility in service options and the shift from focusing on the family to focusing on the individual that accompany this type of switch (Caldwell & Heller, 2007; Rizzolo et al., 2006).

Family Support Programs in one Midwestern State

In the midwestern state where DDS is located, there are almost 90 developmental disabilities agencies administering and funding services for individuals with DD. As outlined in state law, these agencies may use funds to establish FS programs, though it is not required that they do so (State Department of DD website/Current Rules). When an agency does establish a FS program, it has flexibility to create a program that meets the needs of people in the geographical area in which it is located and is within any budgetary constraints the agency faces. According to state rule, if the agency does operate a FS program, it must establish a written policy governing the program that shall:

- specify that individuals or family members may receive FS program funds, and define which family members are eligible,
- describe goods and services that may be purchased with FS program funds,
- address whether or not an income-based fee schedule will be used to determine eligibility and whether documentation of income is required,
- set forth the application process and the process to review and approve/disapprove applications, and
- describe the payment processes. (State Department of DD website/Current Rules)

The state department of DD, which oversees all agencies that provide DD services, previously allocated funds to each agency to fund or partially fund FS programs as part of its annual budget process. In 2020, the state discontinued all allocations for FS programs after several years of systemically reducing these allocations. As a result, some agencies no longer operate a FS program at all.

In February 2022, I completed a survey of 88 DD agencies similar to and including Developmental Disabilities Services which resulted in 79 responses. Results showed that 66 agencies (84%) still operated FS (or similar programs) despite state budget reductions. Of these FS programs, 32 (48%) serve fewer than 100 people, with the smallest programs serving 10 people and the largest serving 3000, almost triple the number of the next largest program in the state. The amount of money a family can access through these programs varies from $350 annually to $4200, with at least 47% of programs providing $1000 or less each year, 12% providing between $1100 and $1900, and 6% providing between $2000 and $4200, with 35% of agencies either not responding to this specific question or without a set maximum amount. It should also be noted that at least 10% of agencies mentioned a reimbursement process, whereby the family must pay for services and recoup the costs from the agency after the fact, although this was not a question in the survey.

Most FS programs offer similar services to the DDS program, including specialized equipment (97%), in-home caregiver supports (95%), recreation memberships or lessons (91%), incontinence and nutrition supplies (91%), summer camp (86%), out of home respite (80%), therapies (73%), home modifications (73%), and transportation (71%). Some agencies reported offering funding for emergency utility payments or clothing purchases on an as-needed basis for individuals with DD. Criteria for enrollment in the program were consistent throughout the responses, with agencies requiring individuals to live with their families (77%) and not be enrolled on a Medicaid HCBS waiver (64%) to access FS program services. Other cited program criteria included families must earn below a maximum family income (33%), individuals with DD must not be in the custody of a local child protection services agency (26%), and must be under the age of 22 (8%).

It is also important to note that 59 of the responding agencies offer additional programs that complement their FS programs. Many of these are called "supported living" or "individualized services" and provide assistance with an individual's utilities and rent, provide funding for employment training, access to technology and computers, driving lessons or assistance with post-secondary education, and many other creative services to benefit individuals with DD in ways that HCBS waivers do not fund. Respondents also described committees they created to review unusual situations and accessing donations to cover the cost of unique requests in order to meet needs, often without set program criteria or hard budget caps.

Applying the Behavioral Model of Health Services to social service programs

Numerous studies have tried to identify and understand why people utilize various health care and social services programs. Findings consistently indicate that some groups are more likely to access services available to them than others (Babitsch et al., 2012). One model that has been used extensively to understand why people use health services is The Behavioral Model of Health Service Use (Aday & Andersen, 1974; Andersen, 1968, 1995, 2008; Phillips et al., 1998).

Developed in 1968 by Ronald M. Andersen, the model has been revised and updated multiple times, but all versions suggest that use of services is a combination of individual predisposing factors, enabling factors, and the need for care (Gelberg et al., 2000). Newer models include a feedback loop, wherein outcomes such as satisfaction with care and perceived health resulting from accessing services then influence subsequent predisposing factors, enabling factors and need for care (Gelberg et al., 2000). Researchers apply the model by selecting different variables from the various domains outlined in Andersen's Behavioral Model for their studies, to determine which, if any, influence service utilization.

The Behavior Model for Vulnerable Populations (BMVP) adjusts need factors to consider those that might impact individuals impacted by homelessness, mental illness, and disabilities. For example, this model includes the traditional individual predisposing needs such as age, gender, race and ethnicity, but adds mobility, mental illness, and literacy (Gelberg et al., 2000). Enabling factors under the traditional model include income and regular source of care, and the BMVP adds ability to negotiate the healthcare system and public benefits (Gelberg et al., 2000). Finally, the BMVP adds vulnerable population health conditions (such as tuberculosis for homeless populations) to the traditional need domain which includes an individual's self-perception of their health or need for care and their evaluated need for care (Gelberg et al., 2000).

Few studies have been conducted using Andersen's model to understand utilization of social service programs, but the revised Behavior Model for Vulnerable Populations is a good fit to inform my research and to utilize in my survey, as described in the methods section.

Action Research Design and Methods

As a professional in the DD field for many years, I find the idea of research that aims to address the needs of a community appealing. Using an approach whereby program participants were able to provide feedback to directly impact the services available to them was also critical to me.

Positioning My Study

Action research methodology uses a cyclical process that includes observation, data collection, development of an action plan, and reflection and revision to allow people to solve a problem in their work setting or community. (Cresswell & Guetterman, 2019; Christ, 2010). Practical action research is one approach that aims to address the specialized needs of a community (Mertler, 2020). My study was a practical action research study because it aimed to achieve a similar objective by investigating how to improve a program that provides services to individuals with developmental disabilities and their families.

More specifically, this research study employed an explanatory sequential action research model. Also called a two-phase model, this approach involves first collecting quantitative data and then collecting qualitative data that helps elaborate on the quantitative findings (Cresswell & Plano Clark, 2018). Using this method allowed me to further delve into the details and richness of the experiences of individuals in the FS program as introduced in the quantitative data, including gathering their unique perspectives on program improvement. Given the critical nature of self-direction in DD services and the importance of budget flexibility in the FS program in particular, it is especially important for individuals and families to have a voice in how the program itself is structured.

Combining a mixed-methods approach with an action research design is a solid methodological strategy to address complex practical problems (Ivankova & Wingo, 2018). This approach to the action research was advantageous because it allowed me to address the practical issue of FS program utilization in a systemic way using multiple methods and thereby producing results that were credible and more scientifically sound (Ivankova, 2017; Ivankova & Wingo, 2018). The engagement of stakeholders in multiple ways also increased the likelihood that I would be able to translate research findings into meaningful outcomes for the FS program and those it does and could serve. I planned to use a grounded theory approach to code and analyze my qualitative data. This approach involves coding interviews by using words that reflected action or feelings of participants, staying open to possible codes rather than using pre-existing codes or predefined ideas (Charmaz, 2006; Kenny & Fourie, 2014). I anticipated that a grounded theory approach would permit me to understand the perspectives of participants in their own words rather than codes I created based on what I anticipated the results would show.

Finally, utilizing this sequential mixed methods approach complimented the two theoretical frameworks I chose for this research. From the quantitative perspective, I used Andersen’s (1995) behavioral model as a framework to look at access to and utilization of services, exploring predisposing factors, enabling factors, and need factors that impact access to and utilization of services. Phenomenology, a qualitative research approach, focuses on how people think about a lived experience (Willis, 2007). The interviews with families enrolled in the FS program provided direct insight into what worked and did not work within the DDS program from their perspective as they support an individual with a developmental disability.

Site and Population

DDS is a government agency in the midwestern United States. Located in a large urban area with a population of over one million people, the agency serves over 10,000 people with developmental disabilities each year. Its mission is to support people with developmental disabilities to live in the community (Developmental Disabilities Services, n.d.). Historically the agency was well known and respected for the provision of both special education services for children along with rehabilitation and training for adults. Over the past fifteen years, the agency closed its schools and began to support children in various school districts throughout the community. In the last five years, the agency also privatized its adult services. The privatization of these direct services resulted in a significant reduction in staff for the agency.

DDS continues to provide services that are vital to the community, including case management, in which employees work with individuals with DD to assess their needs, identify goals, find services in the community, and coordinate and authorize funding for those services. The agency also provides a number of therapies, early intervention services, behavioral health supports, and most importantly, funding for a variety of direct care services that people with developmental disabilities access through private providers. Privatization has allowed the agency an opportunity to focus on how to be more innovative and identify services that can reach more individuals than it previously did when it was a direct service provider. The FS program is one way the agency hopes to serve people that historically have not accessed services from DDS.

The FS program provides flexible but limited funding to individuals with disabilities who are living with their families but are not enrolled in Medicaid waiver programs or receiving other types of funding. An individual typically qualifies for an annual funding allotment of $750 regardless of family income. If family income is below a certain threshold, the individual qualifies for $1500 in annual funding. In 2021 and 2022, the agency temporarily increased those annual allotments by $500 because of enhanced federal funding the agency received related to the COVID 19 pandemic (Developmental Disability Services/*Family Supports*, n.d.). Individuals and families within the program can choose which services they need, with a number of options available including in-home caregiver services, out of home respite, summer camp, specialized equipment, home modifications, training or conferences, and specialized therapy such as music or aquatics. In addition, individuals in the program are able to choose their own caregiver and negotiate payment rates, without having to utilize someone who has been certified by the state department of Developmental Disabilities (Developmental Disabilities Services/Family Supports, n.d). This is a unique and especially well-liked aspect of the program that does not apply to any other DD services.

The DDS FS program has an operating budget of approximately $5 Million for 2022 (Developmental Disabilities Services Annual Plan, 2022). The agency employs one supervisor and two coordinators that oversee the program and work closely with External Agency (pseudonym), with whom the agency contracts to do the day-to-day operations of the program. External Agency processes family applications, maintains data related to individuals in the program, processes invoices to pay providers of services, and purchases equipment or recreation memberships and other items families need (External Agency, n.d.). DDS staff focus on program expansion and outreach, make decisions about services that require large expenditures such as home modifications, and assist with connecting families to agency therapists and other resources when needed. For the purposes of this study, DDS FS program staff collaborated on survey and interview questions and were involved in reviewing themes identified within the data for possible program modifications.

In 2021, the DD Family Support program had 3049 participants. As of the time I prepared to collect data in April 2022, there were 2753 individuals with DD enrolled, with 31% female and 69% male. Of those in the program, 30% identified as Black, 44% as White, 3% as Asian, 5% as two or more races, 3% as some other race, and 15% declined to answer. An additional 9% identified as being of Hispanic origin. Of the 2753 participants, 11% were adults and 89% were children. Ages of individuals enrolled in the program ranged from 2 years old to 68 years old with a median age of 7. The number of people enrolled in the program was expected to rise throughout the calendar year following historical enrollment trends. By the end of 2022, 3819 people had enrolled in the FS program.

Family caregivers for all 2753 participants enrolled in April 2022 received the quantitative “participant” survey. An additional 550 family caregivers of individuals who were previously enrolled in the FS program in 2020 or 2021 but did not enroll in 2022 received the “nonparticipant” survey as described in later sections of this paper.

Researcher Role and Positionality

Positionality is a term used to describe a person's word view and the position they take about a research project and its social context (Holmes, 2020). A researcher's gender, race, ethnicity, (dis)abilities, social class, geographical location, personal history and values all influence their positionality. To help foster a sense of trust in the outcomes of the research project, researchers must employ a reflexive practice to assess and disclose their positionality in their research (Creswell & Gutterman, 2019; Holmes, 2020). Additionally, researchers should reflect on their positionality throughout the research process as positionality is not fixed and a researcher's views and conceptions of their subject matter, participants and the research process may change over time (Berger, 2015; Holmes, 2020). Using this type of reflexive practice helps researchers more accurately capture the views of study participants rather than their own and is a critical step to establishing a quality mixed method study (Berger, 2015; Plano Clark & Ivankova, 2016).

As someone who has worked in the developmental disabilities field for over twenty years, some might consider me an "insider" within the field because of my extensive knowledge of and familiarity with policies, services, concepts, and issues that are important to individuals with developmental disabilities (Holmes, 2020). Other definitions would consider me an "outsider," as I do not have a developmental or intellectual disability, nor am I an immediate family member or caretaker of someone with DD and therefore I cannot truly understand the culture, obstacles, and needs of individuals with DD (Holmes, 2020; Milner, 2007). Being aware of this unique insider/outsider dynamic was especially important when identifying themes and next steps in my research and during the interview process. It was imperative that I was careful with time to allow participants to express their ideas in their own words without interpreting statements through my lens as an administrator in the DD system. Allowing individuals with DD and their families to control the feedback they provide during this research was important to me and in line with my beliefs about person centered planning: that individuals with DD should be considered experts on the care they want and need.

Access

At the time of my research, I was a member of the executive management team in the organization that is the subject of this research, and I reported directly to the agency CEO. I oversaw multiple departments, including the department that administers the FS program. As such, I had access to the data related to the individuals enrolled in the FS program and was able to contact them for purposes of this research.

Throughout my tenure at the organization, I developed close relationships with employees throughout the organization. I previously collaborated with DDS staff on updates to the FS program eligibility and application process, and while they did ultimately report to me, we had a collaborative and transparent working relationship that was useful throughout this project. DDS staff were given the opportunity to provide input into survey questions, review findings, and contribute to action steps for FS program improvement. I also built a trusted network of colleagues around the state through membership and leadership positions on statewide committees. These relationships allowed me to gather the previously reported information about the number of FS programs in the state where the research will take place.

Influence

If research participants were aware of my elevated position within the agency when I interviewed them, it was likely that they may have perceived a power dynamic related to my role within the agency compared to their roles as consumers of FS program services. They may have been uncertain about disclosing their dissatisfaction with services, or they may have been concerned that they would be negatively impacted by sharing negative feedback. On the other hand, they might have seen the interviews as an opportunity to have their input considered by someone who was in a position to take action to directly address their concerns and my influence may have increased their willingness to be candid. It was important for me to be transparent with participants related to the overall goal of the research and plan to improve the program for better access to services, and to reiterate that my role during interviews was primarily as a researcher.

I intentionally tried to create rapport with those interviewed so they would feel safe enough to share information about what was not working in the FS program. Because interviewees received services from a program within my line of oversight, I had to safeguard against making assumptions about what people meant, solving problems they may have experienced, or feeling defensive if they were unsatisfied with their services. Peshkin (1988) suggests that not only must a researcher acknowledge the subjectivity that is likely in qualitative research, but they must also systematically seek out their subjectivity throughout the research process in order to assure it does not impact the research outcomes. Practicing reflexivity via journaling to remain aware of my own feelings and beliefs throughout my research was critical.

Transparency

The more transparent a researcher is with research participants, the more trust and credibility they will have in the project and researcher (Biber, 2017). I shared the goals of my research project with all participants during qualitative interviews. It was important for them to understand that the outcomes of my research may help inform the DD field in our state, but also at the agency where I worked and may have influenced changes to the FS program. In addition, a summary of the research results was made available upon request for anyone who participated in the research process, whether through qualitative or quantitative measures.

Ethics and Political Considerations

While I expected the majority of respondents to the surveys and interview participants to be family caregivers of individuals with developmental disabilities, it was possible that an individual with DD enrolled in the FS program may also have responded and wanted to participate in the research study. In accordance with my own values related to the inclusion of individuals with DD in all aspects in their lives, including research about programs that serve them, I was prepared to welcome individuals with DD as participants.

McDonald and Patka (2012) suggest that in addition to scientific training and a commitment to treating all participants with respect, researchers in the DD field benefit from opportunities to develop positive relationships with individuals with DD and an understanding of their diverse life experiences. Researchers should consider providing multiple reminders to participants with disabilities that they may withdraw from the study at any time, use simple language in questions and consent documents, and researchers should be prepared to rephrase questions or allow for additional time during interviews (McDonald & Patka, 2012). My extensive experience working directly with individuals with developmental disabilities and their families gave me an advantage in terms of my comfort level and ability to create rapport with the individuals I may have interviewed.

Quantitative Data Collection

Two different versions of a survey I created were used to gather feedback from both current program participants and people who were previously enrolled in the program but who were not currently enrolled at the time of my research (non-participants). These two slightly different versions allowed me to more appropriately target questions to survey respondents based on their experiences and compare their responses to determine differences that may have impacted their ongoing participation in the program. Differences in the two versions are described in detail below.

Both groups received the appropriate version of the survey, along with an invitation to participate (Appendix A) and a letter from DDS (Appendix B) supporting the research project and asking them to help improve the FS program by either completing the survey online or on paper and returning the survey using the postage paid return envelope. The letter from the agency explained how survey participation is voluntary and confidential and would not impact eligibility for the FS program in any way. The letter from DDS also outlined a raffle to incentivize participation, as outlined in a separate section below.

Both versions of the survey utilized a variety of question formats, depending on the topic of the question. Some questions used a Likert scale with available answer choices to include strongly agree, somewhat agree, somewhat disagree, strongly disagree, and unsure. Other questions, including those that gather information about demographics, predisposing needs, and which services are most useful, asked participants to select from several multiple-choice options. These types of closed-ended questions allowed for greater uniformity in answers among participants, which were important to ensure that current program services and potential predisposing needs were being evaluated as planned (Aveidan, 2014). Closed-ended questions also allowed for greater ease in terms of data analysis (Avedian, 2014). Each version also included at least one open-ended question to allow participants to provide detailed information from their own perspective that would be impossible to gain if only closed-answer question format was utilized (Avedian, 2014). Specifically, survey respondents were asked to provide suggestions for program improvement or the addition of services which might benefit individuals served. Finally, survey participants were asked to provide the race, ethnicity, age and gender of the individual with DD enrolled in the program but were not asked to provide their name or other identifying information. Given the large number of potential respondents, there was no way to link survey responses back to any participant with the data being collected.

The agency had email addresses for 92% of current and previous participants so surveys were sent via email to those people. Others for whom email addresses were not available received a paper version of the survey and letters via U.S. mail. Approximately two weeks after the survey was emailed or sent via U.S. mail, all respondents received a postcard reminder along with a website link and QR code that people could scan with a mobile device to complete the appropriate version of the survey online via Google Forms instead of on paper if they preferred. Email reminders were sent to people who received the electronic survey approximately one week following the postcards and then again one week later. The online version was designed such that participants were required to provide a response to each survey question before they could advance to the next question. In addition, the online survey had built in logic so that if participants indicated they did not access a specific service like respite, the software skipped the next question asking about the ease of being paid for respite services. This logic was added for the ease of survey participants and to reduce confusion so they would not have to skip questions that did not apply to them. At the conclusion of the survey period, all online responses were downloaded, removed from Google forms, and stored in a folder on a laptop that is protected by a 2-factor identification and encrypted using a 256-bit Advanced Encryption Standard. Paper responses were data entered into the same location for further analysis.

It should be noted that the electronic version of the survey included additional controls (inability to skip questions and logic for contingent questions) that the paper version did not. For these reasons, I preferred completion of the online survey instead of the paper version. However, given the number of people served by DDS that still prefer to communicate via U.S. mail rather than electronic means, the paper survey was an important option. Paper surveys that were returned but not fully completed or that had questions answered but that did not apply based on previous responses were discarded for consistency as described in the data analysis section of this paper.

Current Participant Survey

The purpose of the first version of the survey, referred to as the “current participant survey,” (Appendix C) was to gather information about the participants’ experiences in the program including: usefulness of current services offered, the way in which they first became aware of the program and reason they decided to apply, ease of application and effectiveness of communication from the agency, and suggestions for program improvement. 2753 people who participated in the FS program in 2021 and were already enrolled in 2022 received the current participant survey, which consisted of 17 questions, 2 of which could have been skipped depending on how participants answered questions about which services they utilized.

Non-Participant Survey

The second version of the survey (the “non-participant” survey) was sent to 550 people who did not reapply from 2020 or 2021 to 2022 but were still eligible for the program and asked 18 questions (Appendix D). Several topics from the participant survey were addressed in the non-participant survey including ease of application, usefulness of services offered via the program, and ease of accessing services. Additionally, the survey asked respondents reasons why they did not re-enroll in the program, whether they had any unmet needs the program did not address, and what those unmet needs were. The survey also allowed space to share suggestions for ways to improve the program.

Qualitative Data Collection Procedures

Semi-structured interviews were conducted with 13 respondents from the participant survey and 4 respondents from the non-participant survey who identified a willingness to participate in a conversation about the FS program (Cresswell & Guetterman, 2019, Hesse-Biber, 2017). Interview participants were recruited using a single question on both the current participant and non-participant surveys, asking people to include their name, phone number and email address if they were willing to be contacted for a follow up interview. This identifying information was removed from survey responses before quantitative data was analyzed (Cresswell & Gutterman, 2019).

Because more volunteers indicated a willingness to participate than needed, a purposive sampling method was utilized to obtain a sample that was diverse with respect to race, ethnicity, gender and predisposing factors as identified in the survey (mobility needs, mental health/behavioral needs and communication challenges) (Palinkas, et al., 2015). These interviews covered the same topics discussed above but provided for additional context related to the reasons why these families applied and how they perceived the usefulness of services, which was critical information related to the phenomenological exploration of individuals and families in the FS program as part of my research project.

Prior to the interviews, participants were provided an informed consent document, which included a brief overview of the nature of questions to be discussed. The interviews were audio and video recorded through the Zoom platform. Audio files of the interviews were uploaded for transcription using Otter.ai and the resulting transcript was converted to a Microsoft word document. All audio, video, and transcribed files were stored on a secured and encrypted drive for confidentiality.

Interviews each ranged from 45 to 60 minutes in duration and began with a review of the informed consent document, including the participant’s ability to withdraw from the study at any time without consequence. I also reviewed my role as researcher, my role as an employee of the agency. and my interest in the FS program specifically.

The interviews were semi-structured and consisted of 12 questions. Appendices E and F outline the list of questions utilized. The value of the sequential mixed method design I utilized is that I was able to use the qualitative interviews to further understand the initial quantitative results (Plano Clark & Ivankova, 2016). When the quantitative data suggested unanticipated themes, interview questions were adjusted accordingly prior to the start of any interviews.

Open-ended questions were utilized to prompt participants to discuss their experience with the FS program from their unique perspectives, and follow-up questions were used as necessary to prompt participants for further elaboration on their responses. Notes were taken during the interviews to document any researcher observations or reflections that were noticed during the interviews (Cresswell & Guetterman, 2019). Participants selected the date and time of their interview based on their convenience to assure the least number of distractions or disruptions for them during the interviews, and to demonstrate respect for them as participants in the research process.

Integration

Integration, or the way in which researchers interrelate quantitative and qualitative data, is an important part of mixed methods research and is one of the benefits of this research model (Plano Clark & Ivankova, 2016). I integrated data first during the data collection stage, by connecting the quantitative survey results to inform the qualitative interviews to better understand the barriers families may face in the FS program and to adjust interview questions. I also integrated data during the analysis stage by showing how the interview data deepened the understanding of the survey findings. This integration offered the best opportunity for improvement to FS programs by assuring a relevant, trustworthy series of conclusions.

Compensation

Because improving the FS program is a high priority for the DDS, the agency agreed to incentivize participation in both types of data collection through use of drawings for gift cards for participants. While payment for participation in research is not unusual, it had to be done thoughtfully in order to avoid unintended coercion of participants. Many ethics committees warn against compensation that is significant enough to encourage participation even when it is against the best interests of the potential subjects, and some even express concern that such inducements may invalidate informed consent (Stones & McMillan, 2010). However, this is more likely to be a concern in medical research or studies where there may be significant physical or psychological risks to participants compared to this research design.

When research involves an individual with a developmental or intellectual disability or someone who is a member of another vulnerable population (mentally ill, homeless, economically disadvantaged), researchers must be especially thoughtful about the type of incentives or compensation they offer as they may be even more likely to coerce participation. Even so, McDonald & Patka (2012) found that in a study of 17 researchers and ethics review board members who conduct DD research, many agreed that it is reasonable to compensate individuals with DD using incentives that are "attractive, fair, and noncoercive." While it is difficult to decide on the right amount for an incentive, it was clear that it should be equal to what someone without a disability would earn or could win. In the case of this study, most participants were expected to be family caregivers of individuals with DD, not persons with disabilities themselves, although that was possible. As such, the type and amount of incentive was carefully chosen as to not coerce anyone into participating.

Each paper survey included a separate slip of paper on which participants could fill in their name, phone number and email address if they wanted to be entered into the drawing. The instructions indicated that when the survey was mailed back, the separate slip would be removed from the rest of their survey before any data was analyzed so their answers to other questions would remain anonymous. The online survey offered a link at the end of the survey to a separate online form where participants could enter the same identifying information that was stored apart from survey data and used for purposes of the drawing only.

On a pre-identified date following the survey collection period, five names from all survey respondents were randomly selected as winners, notified by phone and email, and each received a $50 gift card. The same process was repeated on the next consecutive business day, allowing for a total of ten (10) $50 gift card winners for the quantitative portion of the study. As required by the University of Dayton IRB Raffle Policy, all participants had an equal chance of being selected, even if they did not complete the survey. Details regarding the drawing were provided to participants at the time they received the survey.

The agency also provided five (5) $50 gift cards for a drawing that included everyone who agreed to be interviewed for the qualitative interview. All details about personal data storage and gift card distribution were the same as described for the quantitative survey incentive including eligibility in that people were eligible even if they were unable or unwilling to participate in the interview after volunteering.

Data Analysis Procedures

Quantitative Analyses

Data cleaning consisted of removing partial surveys or surveys with obvious signs of random answer patterns from the dataset. Once cleaned, data was transferred into

SPSS version 27 for analysis. The demographic information including race, ethnicity, gender, and age was examined for two groups: those enrolled in the program in 2022 (participants), and those that were enrolled in the program in 2020 or 2021 but did not re-enroll in 2022 (non-participants) using multivariate analysis of variance (MANOVA) tests in order to further identify whether predisposing factors suggested by Andersen's model (1995) impacted service satisfaction or willingness to recommend the program.

Mean and median were calculated and reported for most questions. Visual representations of questions with multiple choice answer options were utilized for easy interpretation.

Qualitative Analyses

Coding, or categorizing and organizing segments of data to define what the data are about, is the first step in analyzing qualitative data (Charmaz, 2006; Cresswell & Guetterman, 2019). I used a grounded theory approach, which includes two main phases. First, I completed an initial reading of each transcript and coded various phrases, lines, or segments using words that reflected action or feelings of participants, staying open to possible codes rather than using pre-existing codes or predefined ideas (Charmaz, 2006; Kenny & Fourie, 2014). The second phase included a refocused coding, wherein I identified codes that occurred repeatedly or were significantly related to the experience of families of individuals in the FS program. These codes then informed the themes that emerged from the interviews collectively (Kenny & Fourie, 2014). See Appendix G for a sample of my qualitative analysis.

Trustworthiness, Credibility, and Transferability

Trustworthiness is a term to describe the methods researchers use to produce results that can be accepted as credible and persuasive by others (Plano Clark & Ivankova, 2016).

Dependability

Dependability is the extent to which others could replicate a research study and expect consistent findings (Hesse-Biber, 2017). Research methods have been clearly described and both survey and interview questions attached so that others can replicate the research design.

Confirmability

Confirmability assures that the researcher's findings result from the researcher's data, rather than the researcher's bias or personal motivations (Hesse-Biber, 2017). Because of my close relationship with the FS program and the agency, I established several strategies to aid in the confirmability of the study. First, I identified my potential biases and the power dynamic related to my role in the agency and the program and disclosed them in this study. I also engaged in writing memos following each interview to reflect on the effectiveness of the interview and capture any impressions about the interview itself. Using memos is a way to provide an audit trail and rationale for decisions that I made in my research, which can also enhance trustworthiness.

Credibility

Credibility is the extent to which the study results are seen as accurately portraying the study participant's experience, or the truth of the research findings (Plano Clark & Ivankova, 2016; Hesse-Biber, 2017). Member checking is one important method of increasing credibility in a qualitative or mixed-method study. Following each interview, the transcriptions were compared against the recorded video to ensure accuracy and transcripts shared with participants to confirm that they were accurate and adequately portrayed what participants were trying to share.

To triangulate results, I reviewed interview results and themes with the FS staff at DDS to ensure that I understood the terminology used by participants. Throughout the design of the study, I completed an external audit by reviewing my work with and seeking feedback from peers and FS program staff regarding interview questions and themes from interviews and survey results (Hesse-Biber, 2017).

Transferability

Transferability is the notion that the study's findings are applicable to other contexts (Hesse-Biber, 2017). Given the number of FS programs in the state where DDS is located, and the similarity of those programs to the DDS FS program, it is likely that the quantitative results of the study are highly generalizable to other agencies.

The qualitative stage of this study consisted of interviews with 13 family caregivers of individuals with DD. All interviews were completed within one month, and each lasted between 45-60 minutes. Because convenience sampling was utilized the sample was impacted by participant willingness to volunteer, though the invitation was open to a diverse group of over 2700 people enrolled in the FS program. Qualitative findings were based on the presence of thick and rich descriptions derived from the data and integrated with the quantitative findings at several points (Hesse-Biber, 2017; Plano Clark & Ivankova, 2016).

CHAPTER TWO

RESULTS

The purpose of this study was to understand the lived experiences of people with developmental disabilities and their families enrolled in a Family Supports program, as FS programs may be a viable option to provide options to people with DD and their families who are waiting for services. Specifically, I was interested in what factors influence people to utilize the program, whether they found services useful, and whether there were differences in groups who were satisfied with the program and those that were not. I utilized an explanatory sequential action research model, which involves first collecting quantitative data and then collecting qualitative data that helps elaborate on the quantitative findings (Cresswell & Plano Clark, 2018). The following sections display and explain the information gathered through quantitative and qualitative data gathering.

Quantitative Results

Quantitative data was gathered in the form of online surveys via Google Forms and paper versions mailed to individuals for whom we did not have email addresses. Two different versions of the surveys were designed for current program participants and those who were no longer enrolled in the program. Quantitative data were analyzed using IBM SPSS Statistics (Version 27) predictive analysis software.

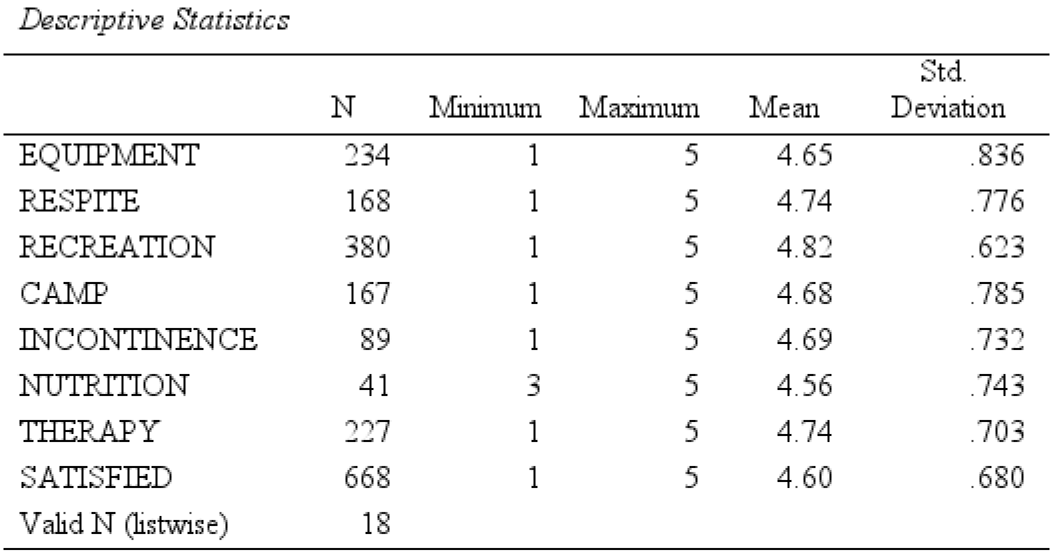
Descriptive Statistical Analysis

A total of 2753 surveys were sent to current FS participants (2622 via email and 131 by US mail), and 668 completed and unduplicated responses were received, for a response rate of 24%. A total of 550 nonparticipants received the alternate version of the survey (429 by email and 121 by mail), and 39 completed and unduplicated responses were received, for a response rate of 7%. Surveys that were not fully completed were not utilized for data analysis.

Helpfulness/Usefulness of Services and Overall Satisfaction. People currently and previously enrolled in the program were asked whether they found their services to be useful/helpful by ranking them on a scale of 1 (not at all helpful) to 5 (very helpful). Table 1 shows that individuals and families enrolled in the FS program (participants) indicated that the services they used (specialized equipment, respite, recreational activities, camp, nutrition, incontinence supplies, and therapies) were helpful or very helpful to them and that they were satisfied with the program overall.

Table 1.

Usefulness of services utilized and overall program satisfaction for FS program participants.



Descriptive Statistics

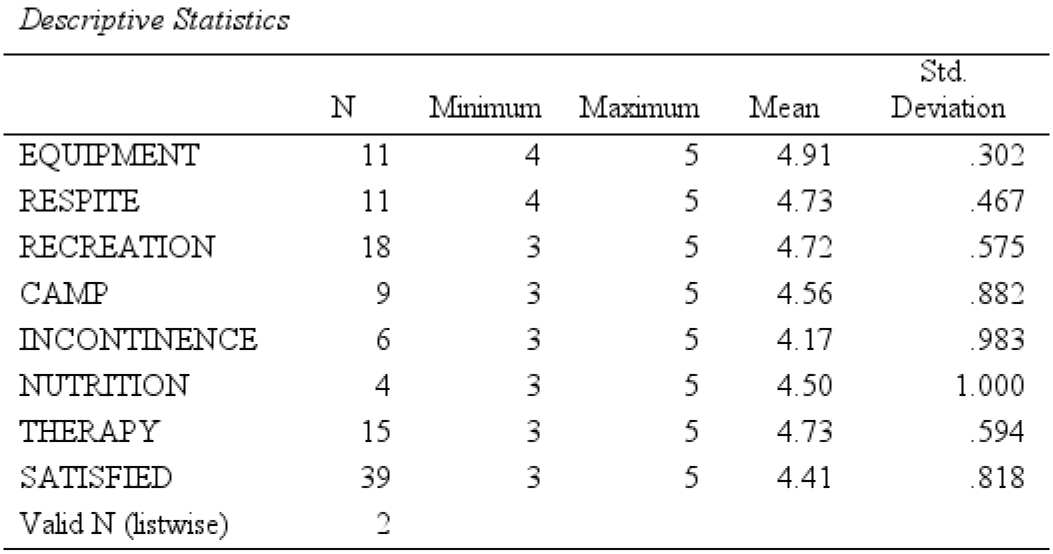
	N	Minimum	Maximum	Mean	Std. Deviation
EQUIPMENT	234	1	5	4.65	.836
RESPITE	168	1	5	4.74	.776
RECREATION	380	1	5	4.82	.623
CAMP	167	1	5	4.68	.785
INCONTINENCE	89	1	5	4.69	.732
NUTRITION	41	3	5	4.56	.743
THERAPY	227	1	5	4.74	.703
SATISFIED	668	1	5	4.60	.680
Valid N (listwise)	18				

Note. Surveys used a Likert scale where 1 = Very Unhelpful, 2 = Somewhat Unhelpful, 3 = Unsure, 4 = Somewhat Helpful, 5 = Very Helpful.

Similar to people currently enrolled in the FS program, those individuals not currently enrolled in the FS program but who previously used services (non-participants) indicated the services they used were helpful to them as noted in Table 2. Service satisfaction in both groups was an important measurement because it may speak to the viability of FS programs as an option for people with DD who are underserved.

Table 2

Usefulness of services utilized and overall satisfaction for people previously enrolled in the FS program



Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
EQUIPMENT	11	4	5	4.91	.302
RESPITE	11	4	5	4.73	.467
RECREATION	18	3	5	4.72	.575
CAMP	9	3	5	4.56	.882
INCONTINENCE	6	3	5	4.17	.983
NUTRITION	4	3	5	4.50	1.000
THERAPY	15	3	5	4.73	.594
SATISFIED	39	3	5	4.41	.818
Valid N (listwise)	2				

Note. Surveys used a Likert scale where 1 = Very Unhelpful, 2 = Somewhat Unhelpful, 3 = Unsure, 4 = Somewhat Helpful, 5 = Very Helpful.

Predisposing Factors (Demographics)

According to Andersen's Behavioral Model for Vulnerable Populations, it is important to consider predisposing factors which may impact an individual's utilization of social and health care services (Gelbert et al., 2000). Predisposing factors may include factors such as age, race and ethnicity, gender, mobility, mental illness, and literacy, among others (Gelbert et al., 2000). For purposes of this study, information about the gender, race, ethnicity, and age of people either currently enrolled in the program or previously enrolled was collected. Respondents were also asked whether the person in the FS program experienced challenges related to personal mobility, communication, and behavioral health/mental health, as these are not uncommon in the DD population and could certainly impact use of DD services, including the FS program. Information about race, ethnicity, age, and gender of the survey respondents, who were typically caregivers, was not collected.

Traditional demographic factors including gender, race, ethnicity, and age are shown in Table 3. The majority of both participants and non-participants were male (61.7% for Participants and 62% for Non-Participants) and White (50.9% for Participants and 43.9% for Non-Participants). Ages ranged from less than one year to 62 years old for FS participants with the largest percentage in the 0-2 year group (29%) followed by the age 6-12 year group (25.7%). Non-participants varied from 1 to 30 years old, with the highest number in the 13–21-year group (33.3%) followed by 0-2 year group (30.7%).

A limitation of this study is the way in which race and ethnicity information was gathered. DDS uses the race categories utilized by the United States Census Bureau as of the 2020 census. These race categories do not include a Latino or Hispanic option. My survey used the same race categories and offered Hispanic as an ethnicity option (11.1% of participants and 18% of non-participants chose this option). Respondents had to first choose a race option that was not Latino or Hispanic, making it difficult to determine how many people with DD might truly be in this group for my study if they would not have had to choose a race other than Hispanic or Latino first.

Table 3

Demographics of FS program participants and non-participants

	FS Participants		**Non-participants**	
Gender	**N (668)**	**%**	**N (39)**	**%**
Female	243	36.4%	13	33%
Male	412	61.7%	24	62%
Non-binary	01	0.1%	0	0%
Prefer not to Answer	12	1.8%	02	05%
Race				
American Indian/Native American	02	0.2%	0	0%
Asian	17	2.5%	0	0%
Black/African American	193	28.9%	09	23.0%
Native Hawaiian/Pacific Islander	0	0%	0	0%
Other Race	28	4.2%	01	2.5%
Two or More Races	52	7.8%	09	23.0%
White	340	50.9%	17	43.5%
Prefer not to Answer	36	5.4%	03	8.0%
Ethnicity				
Hispanic	74	11.1%	07	18.0%
Not Hispanic	554	82.9%	31	79.0%
Prefer not to Answer	40	6.0%	01	3.0%
Ages				
0-2 years	193	29.0%	12	30.7%
3-5 years	138	20.7%	07	17.9%
6-12 years	172	25.7%	06	15.3%
13-21 years	148	22.1%	13	33.3%
22-39 years	14	2.1%	01	2.5%
40-59 years	02	0.2%	0	0%
60+ years	01	0.1%	0	0%

Inferential Statistical Analysis for Predisposing Factors

Two of my research questions asked whether there were differences in perceptions of service usefulness, overall program satisfaction, and willingness to recommend the program to others between groups with different demographic characteristics. MANOVA tests indicated no significant differences in ratings of usefulness of all seven FS services (equipment, respite, recreation, camp, incontinence, nutrition services, and therapy), overall program satisfaction, and willingness to recommend the FS program related to differences in race, gender, or age across the entire group of survey respondents, including participants and non-participants. Individual ANOVA of these same variables confirmed that there were not significant differences for these factors within the program participants or non-participants groups separately.

I also completed MANOVA tests to determine whether there were differences overall between program participants and non-participants. My analyses revealed there was a significant difference in perceptions of usefulness of services between program participants and non-participants ($F(8,11) = 12.12$, $p < .001$, partial eta squared 0.90, observed power = 1.00). Pillai’s Trace results were reported due to a significant Levene’s Test of Homogeneity of Variances.

Differences in ratings for each of the FS services between program participants and non-participants are depicted in the figures below. There was a significant difference in ratings of usefulness for the camp and incontinence services between program participants and non-participants ($F(1,18) = 4.356$, $p <.05$, partial eta squared 0.294, observed power = .736). People currently enrolled in the program rated the usefulness of camp and incontinence services significantly higher than those not enrolled in the program (Figures 4 and 5).

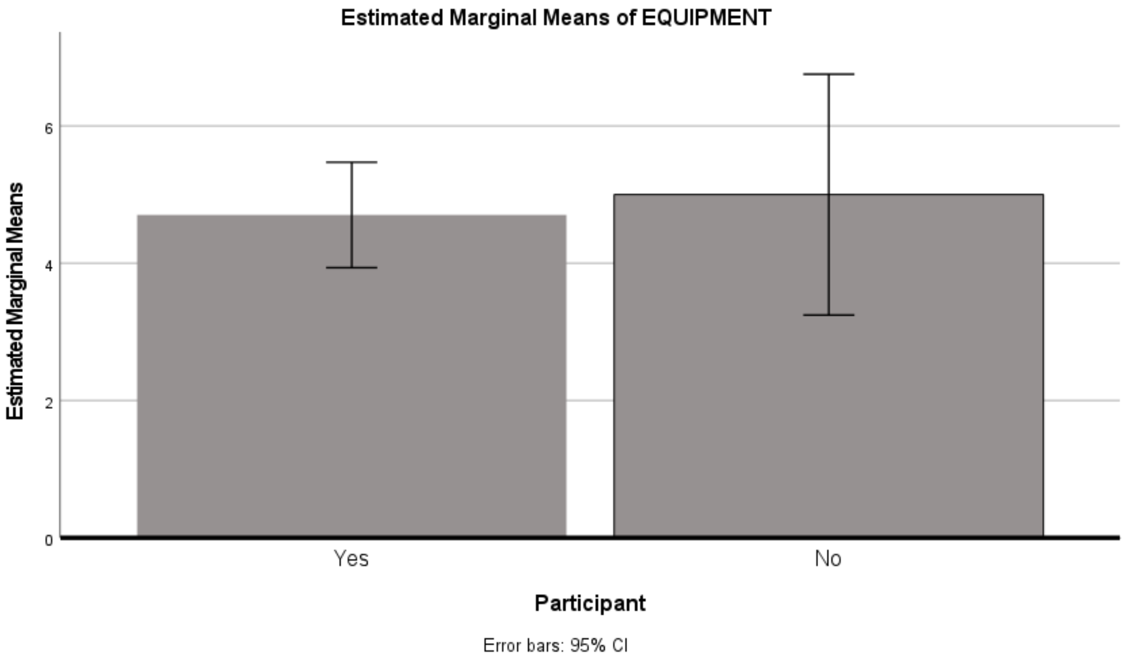


Figure 1

Perceptions of usefulness for participants and non-participants for Equipment

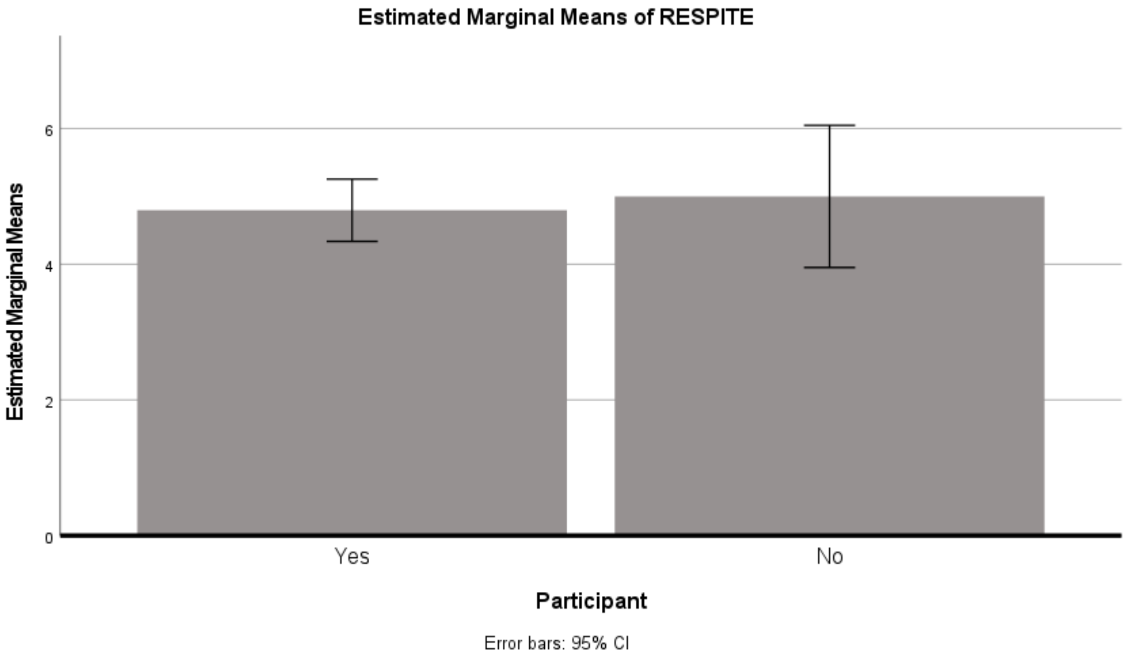


Figure 2

Perceptions of usefulness for participants and non-participants for respite

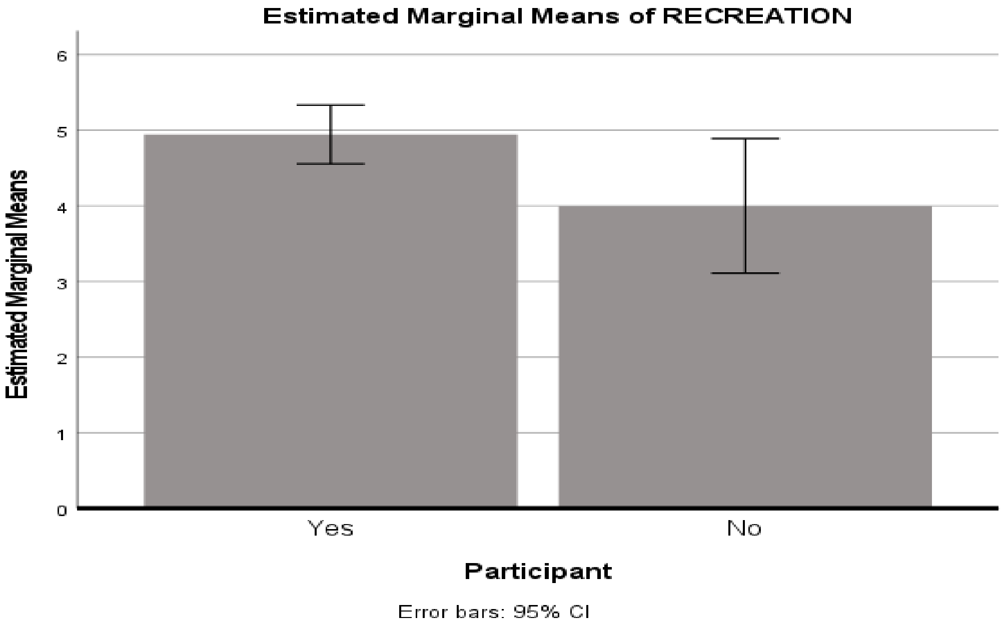
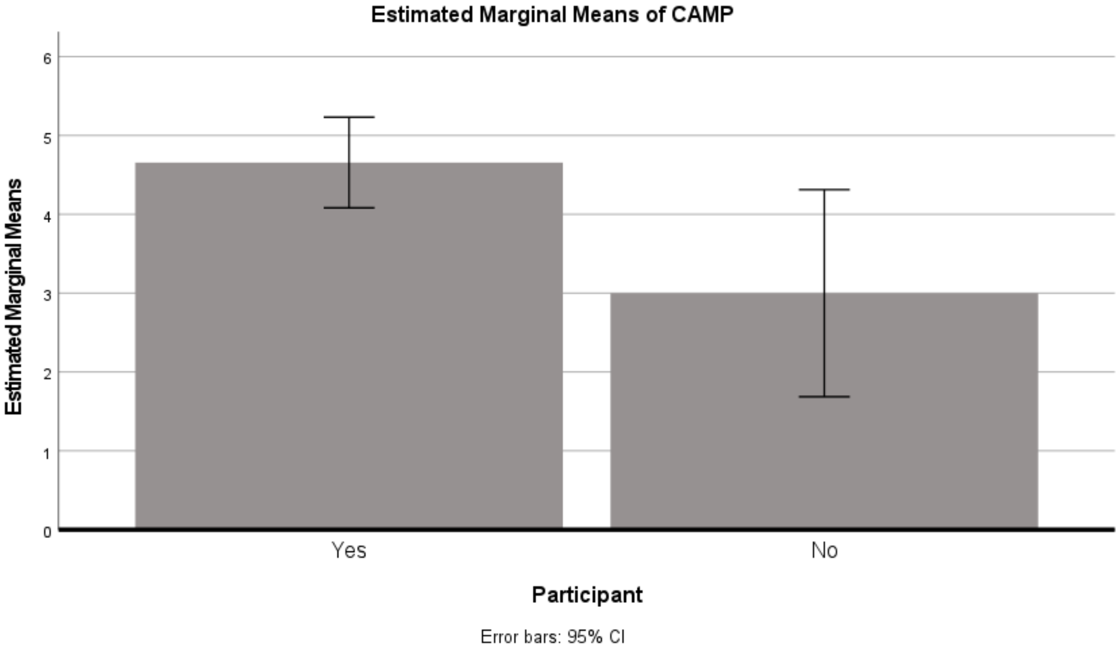


Figure 3.

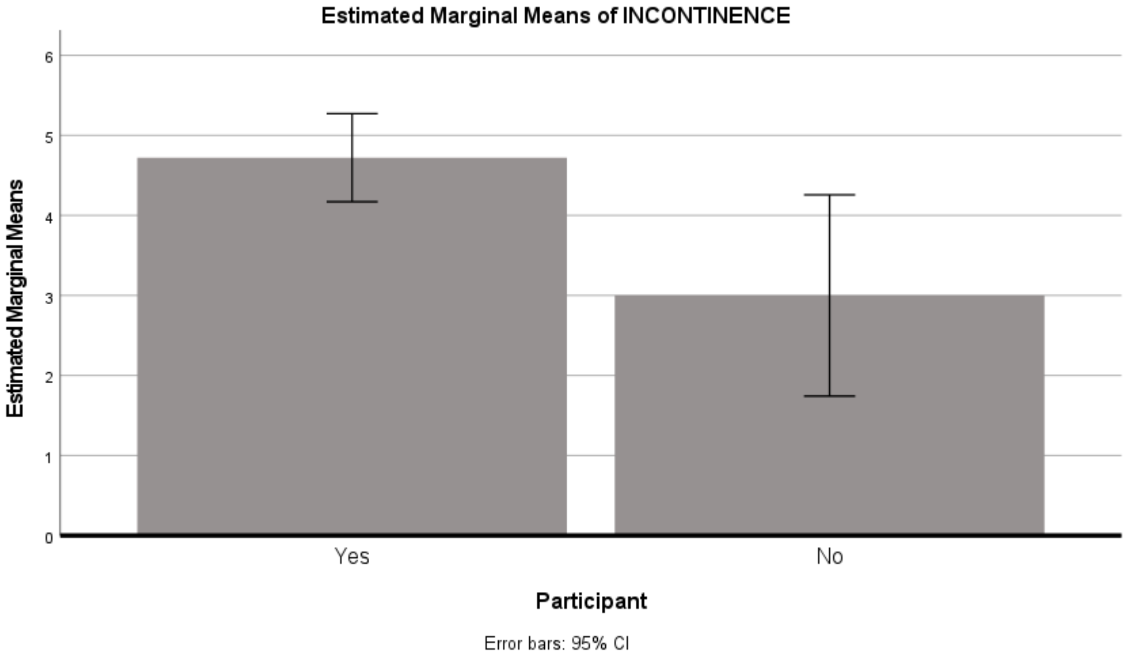
Perceptions of usefulness for participants and non-participants for recreation



Note. Camp results are significant at $p < .05$

Figure 4

Perceptions of usefulness for Participants and non-participants for camp



Note. Incontinence Supplies results are significant at $p < .05$

Figure 5

Perceptions of usefulness of participants and non-participants for incontinence supplies

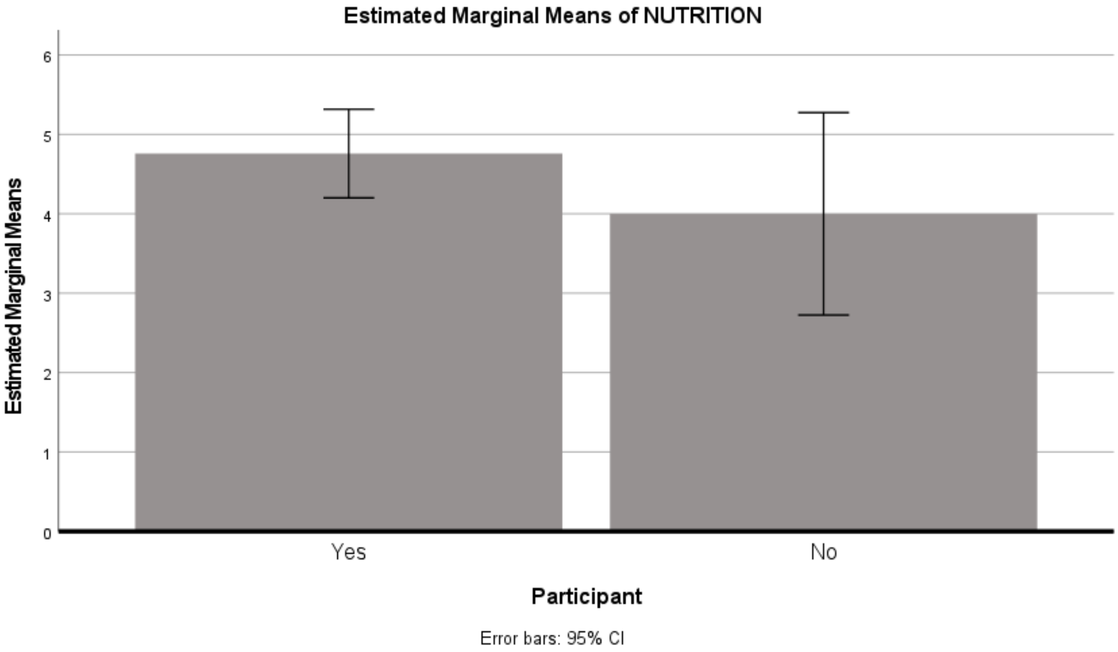


Figure 6

Perceptions of usefulness for participants and non-participants for nutrition supplies

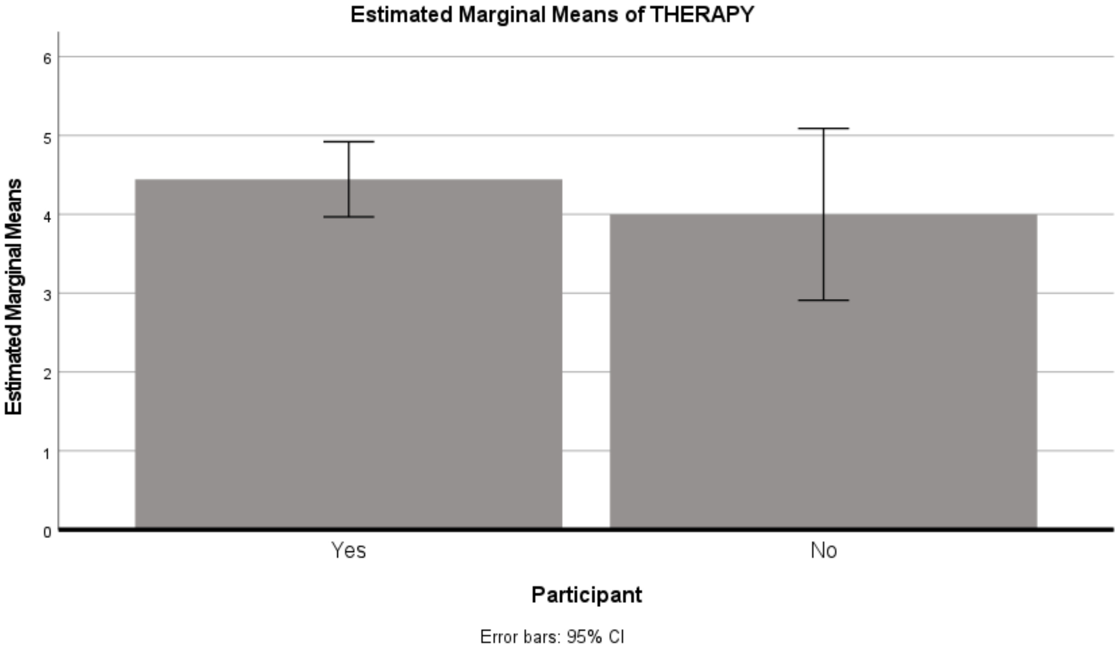


Figure 7

Perceptions of usefulness for participants and non-participants for therapy

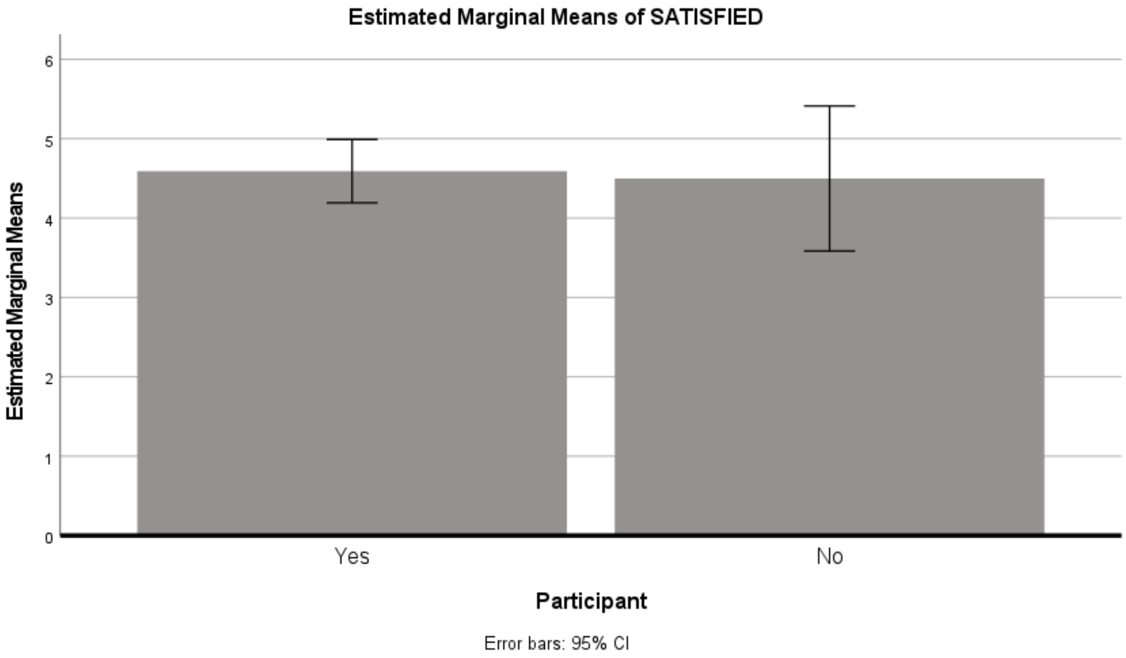


Figure 8

Perceptions of overall FS program satisfaction for participants and non-participants

Need Factors (Mobility, Behavioral/Mental Health, Communication)

Data show that both participants in the FS program and those not participating in the program have need factors, according to Andersen’s model (1995), related to challenges they experience with mobility (18% for participants, 31% for nonparticipants), communication (69% for participants, 59% for nonparticipants) and/or behavioral health or mental health (49% for participants, 46% for nonparticipants). Many people reported a need in more than one of these areas, which is why the totals add up to more than 100% for each group. Only 15% of FS participants and 8% of nonparticipants reported experiencing none of these challenges. This data is reflected in Figure 9.

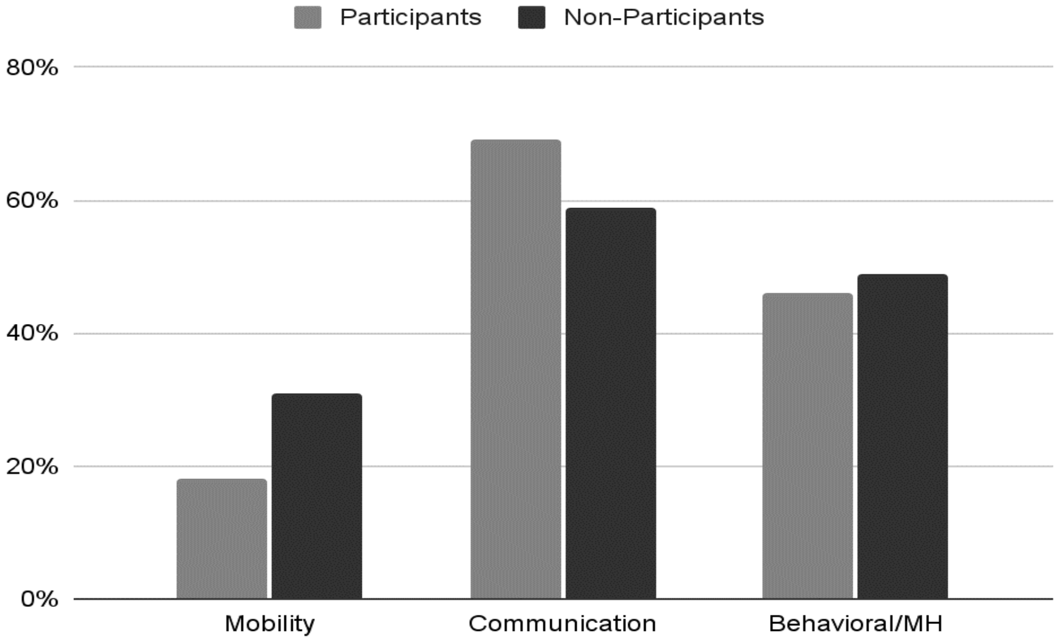


Figure 9

Percentage of participants and non-participants with need factors

Inferential Statistical Analysis for Predisposing Factors

MANOVA tests indicated no significant differences in ratings of usefulness of all seven FS services (equipment, respite, recreation, camp, incontinence, nutrition services, and therapy), overall program satisfaction, and willingness to recommend the FS program related to the presence of mobility, communication or behavioral/mental health needs in participants or non-participants.

Qualitative Results

Qualitative data were gathered via interviews held via Zoom, reviewed as recorded Zoom sessions, and transcribed using Otter.ai software. All survey respondents were asked if they would be interested in participating in an interview to further discuss their current or previous experiences with the FS program. Of those currently enrolled in the FS program, 314 individuals (47%) indicated willingness to participate in interviews, and 17 (44%) of nonparticipants answered that they would be willing to be interviewed. For those currently enrolled in the program, I used a purposive sampling method to obtain a sample that was diverse with respect to race, ethnicity, gender, age, mobility challenges, behavioral health/mental health challenges and communication challenges. I attempted to use a similar method for nonparticipants, but when I contacted people who indicated interest, I received limited responses to my follow up emails and text messages. The four nonparticipant interviews I conducted were with the only people who responded to requests to schedule time with me.

Table 4

Demographics of people with DD whose caregivers participated in interviews

	FS Participants		**Non-participants**	
Gender	N (13)	%	N (4)	%
Female	5	38.50%	2	50.00%
Male	8	61.50%	2	50.00%
Non-binary	0	0%	0	0%
Prefer not to Answer	0	0%	0	0%
Race				
American Indian/Native American	0	0%	0	0%
Asian	1	7.70%	0	0%
Black/African American	5	38.50%	1	25.00%
Native Hawaiian/Pacific Islander	0	0%	0	0%
Other Race	0	0%	0	0%
Two or More Races	1	7.70%	1	25.00%
White	6	46.10%	2	50%
Prefer not to Answer	0	0%	0	0%
Ethnicity				
Hispanic	2	15.40%	0	0%
Not Hispanic	11	84.60%	2	100%
Prefer not to Answer	0	0%	0	0%
Ages				
0-2 years	1	07.7.%	0	0%
3-5 years	2	15.40%	0	0%
6-12 years	6	46.10%	1	7.70%
13-21 years	2	15.40%	01	7.70%
22-39 years	2	15.40%	2	15.40%
40-59 years	0	0%	0	0%
60+ years	0	0%	0	0%

As described in Chapter 1, interviews were semi-structured and lasted approximately 60 minutes each. All interviews were with the family caregiver of the individual with DD, but in 59% (10) of the interviews, the person with DD joined the Zoom meeting for at least part of the interview. If the individual was able to participate verbally, I directed questions to them whenever possible. In all cases, I introduced myself and thanked them for being part of the interview, and engaged in conversation with them while they were present.

Because qualitative interviews were conducted after analysis of my quantitative survey results, I did adjust some questions from the initial interview script initially designed (Cresswell & Plano Clark, 2018; Ivankova et al., 2006). I separated the question about applying for the program and accessing services into two distinct questions for both participants and nonparticipants. Because several comments in the quantitative survey mentioned the financial burden of caring for someone with DD, I added a question about the financial impact interviewees experience related to supporting someone with DD to both interview scripts. Finally, I added a question to the FS participant interviews about their interest in an option for reimbursement for services within the FS program, as this was also a theme in survey comments.

Chapter 1 describes the methods I planned to use to produce results that are dependable, confirmable, credible and transferable. All of these strategies were utilized in my research, including utilization of memos, comparing transcripts against video recordings, member checking of transcripts, triangulation of results, and inclusion of both survey and interview questions and descriptions of methods.

I utilized a grounded theory approach to coding my qualitative data. First, I did an initial reading of each transcript and coded phrases, lines, or segments using words that reflected action or feeling of participants rather than using predefined codes (Charmaz, 2006; Kenny & Fourie, 2014). Next, I completed a refocused coding of each transcript where I identified themes that occurred repeatedly or significantly related to the experience of people enrolled in the FS program. These codes informed the themes identified from the interviews collectively (Kenny & Fourie, 2014). See Tables 5 and 6 for a list of themes and subthemes that emerged from FS participant and nonparticipant interviews. Appendix G provides an example of interview coding.

Overall, interviews with participants in the program highlighted six main themes. First, participants repeatedly stated that the program was helpful to them and they were appreciative of both the staff they worked with and of the services offered. Some participants indicated that they would be grateful for an increase in the annual allotment for services, but the current amount is helpful. Second, interviews revealed that caregivers experience several administrative limitations or burdens that made it difficult for them to access services or limited their ability to plan in a person-centered way for the person with DD. For example, because of the requirements for additional approvals for equipment and the limitations on types of equipment that could be purchased with FS program funds, participants could not buy the items they believed were most needed. One interviewee said, “We know what my daughter needs. A play kitchen would make her want to pull herself up and she would stand while she played. For her and her needs, that really is adaptive.” Another interviewee commented, “I know my son best, and we wanted some sensory items that were only a few hundred dollars total. I feel like I should have been able to spend the money without going through therapists on that because it would have really helped him. It shouldn’t be hard.” A third participant commented that her son got out of the house and was lost. She wanted to buy him a bracelet with his name and phone number on it because he could not communicate verbally with anyone when he was found. “By the time I would have had to get a therapist and do the forms it would have taken a long time. He needed it right away in case he got out again so I just bought it instead of using FS money."

The third theme that emerged from interviews was that caregivers did not have enough information about the program, including what services were available and how to access them. One participant said, "If there was a list of places where we could go for lessons or activities, that would be so helpful. I don't have the time or energy to call a bunch of places." Another commented, "Last year we used our money on memberships to the zoo and aquarium because I didn't want to lose the money. Later I found out it could have paid for swimming and karate which would have been much better for us." "It is hard to know what is out there, I can't seem to figure it out on my own. It's like you need a really good list, or website to help me," said a third participant.

The fourth theme I identified through interviews was that caregivers experience a significant amount of emotional stress that comes with providing care for an individual with DD. While several participants indicated that they felt supported by programs like FS, and by family, friends, and other resources, 100% of interviewees indicated that the developmental disability of their family member adds stress to their lives. One participant indicated that for many years she thought, "I don't know if I am going to make it. I can't do this anymore." Another parent stated "I used to look at people and think, I am really struggling here. Can you see it? Do you hear me?" A third caregiver stated, "If you aren't a caregiver, it's hard to understand. My son's disability is everywhere. It impacts everything we do. Every place we go. Every relationship we have. We can't escape it. Even when I have a few minutes to myself, I am thinking about him and what he needs. It's really hard." Over two-thirds of participants (76.9%) specifically mentioned feeling isolated and alone in dealing with the challenges related to their family members' DD, even when they had supportive networks around them.

The fifth theme resulting from these interviews related to the additional cost of caring for a family member with DD. I added this question to the interviews after review of the quantitative data analysis, where finances were mentioned repeatedly. Of the 13 interview participants, 12 (92%) indicated there was a significant negative financial impact on the family related to the disability. Interviewees were asked if they could estimate how much additional money they spent on the needs of the person with DD. Responses ranged from approximately $1200 per year to over $78,000 per year for additional costs related to the developmental disability diagnosis. One participant said, "People look at us and think, well, they live in a nice house and have good jobs. I don't want people to think we are just taking county money. But I wish people could audit our finances, and they would be like, holy cow, I can't believe how much you spend helping your kids."

Finally, I asked interviewees if they had needs that were unmet even though they were enrolled in the FS program. There were no overarching themes identified, but participants identified 7 things they would like to see covered by the program, to increase their ability to self-determine the services needed by the person with DD.

Table 5

Family Supports Participants Interview Themes

Overarching Themes	Subthemes
Positive Aspects of FS	Application is very simple (10) Appreciate program (9) Any amount of $ allocation is helpful (8) FS Staff are kind (6) Usefulness of program outweighs any admin difficulty (4)
Services difficult to Access/Limit Choice	Equipment - too much scrutiny; many things denied (6) Equipment -hard to find a therapist (5) Equipment - forms are complicated (5) Camp - camps fill up before can get registered (6) Camp - don’t know that all camps are covered (2) Website - hard to find forms (2) General - time to process orders is lengthy; can limit how we spend the money (5)
Not enough information	Recreation - not sure what activities are available (9) Respite - unaware of family chosen caregiver option (4) Respite - not sure what options are for respite (3) General - wish I knew about the program earlier (6)
Stress and Emotional Toll	Stress for caregivers (10) Stress for person with DD (5) Many sacrifices (8) Isolating (10) Exhausted/tired (13) Struggling (13) DD impacts every area of life (8)
Financial expenses	Special school (3) Supplements/Food for gut therapy (1) Recreational activities (5) Equipment (4) Doctor and medication copayments (6) Alternative therapies (acupuncture, massage) (2)
Unmet needs	ABA therapy (4) Social Skills group/Socialization options (7) Parent/caregiver support group/meetings (6) Transportation (5) Help with sensory needs (2) Vitamins, alternative therapies (acupuncture) (2) Planning for the future (3)

The second group of interviews was completed with people who were previously enrolled in the FS program but were not at the time of the interview. Three interviewees (75%) stated that they were no longer enrolled in the FS program because they got the service/item they needed, and they did not have a current need. Each confirmed they would reapply for the program if a new need arose. The fourth indicated that they did not feel the program covered what they wanted (ABA therapy for their adult child) but if they again needed something that was covered by the program, they would contact DDS. One interviewee stated “We don’t need too much right now. I’d rather save the program for someone who has it harder than us. We will find you when we need help again.”

Feedback from the non-participant group included frustration with the administration of some services, including equipment, camp and respite. However, during the interviews I discovered that many of these challenges had already been addressed by simplifications put into place by the agency within the last three years. The interviewees were not aware because they had not tried to access those services since the program changed. For example, feedback from one interviewee was that people should be able to use their FS allocation for camps that are not designed specifically for individuals with DD. This policy was changed by the agency over three years ago, and now people can attend any camp they select. Another interviewee stated that her daughter needed an iPad to help communicate and the program did not cover tablets even when a therapist recommended them. The program funding could be utilized for iPads and similar devices for communication at the time of her interview. A third interviewee said, “I just never felt comfortable leaving my child with someone I didn’t know for respite, although I really could have used the help.” This person was not aware of the family-chosen caregiver option available through the FS program, whereby families can choose a friend or relative that is not certified to care for the person with DD.

Similar to FS participants, non-participants highlighted the strain that comes with being a caregiver to someone with DD. In these interviews, 100% of non-participants stated that they experienced stress and feelings of tiredness or exhaustion related to providing care. Half of non-participant interviewees also stated they felt isolated at some time related to their caregiver role. Finally, all non-participants talked about the added financial expenses related to providing care for individuals with DD. Interviewees indicated that it would be very helpful if the FS program covered things like recreational activities, items, and doctor or medication expenses. The program does cover recreational activities and items but does not reimburse for medical copayments.

Table 6

Family Supports Non-Participant Interview Themes

Overarching Themes	Subthemes
Difficulty with services - already addressed by the agency	Camp - should be able to go to a non-adaptive camp (2) Camp - Some camps won't take FS money (2) Equipment - need electronic device for communication (1) Equipment - why does it have to be adaptive to qualify/review too strict (3) Respite - I could not find caregivers (1)
Stress and Emotional Toll	Stress for caregivers (4) Isolating (2) Exhausted/tired (4)
Financial expenses	Special school (1) Recreational activities (4) Items person loves but breaks repeatedly (1) Doctor and medication copayments (3)
Positive Themes	Appreciate program (3) FS Staff are kind (3)

Mixed Methods Results

In this explanatory sequential mixed methods design, the collection and analysis of qualitative data occurred after the analysis of quantitative data in order to further explore findings identified in the quantitative portion. The qualitative findings demonstrated convergence with the results of the quantitative survey and the interviews helped better explain comments made in the quantitative surveys.

Discussion

This study was designed to understand the factors that influence people to utilize (or not utilize) the FS program, and to measure how useful the program services are to people with DD and their families. Research questions also asked if there were relationships between satisfaction and demographic characteristics or specific need factors of people served.

Both participants enrolled in the program and those previously enrolled gave similar ratings (helpful or very helpful) to program services, were satisfied or very satisfied with the DDS FS program, and willing to recommend it to others. Participants did give overall higher ratings of service usefulness than non-participants, which may explain why non-participants are no longer enrolled in the program. If they didn’t find services as useful as they needed, the program may not have been worth the time and effort required to re-enroll or access services.

Program participants specifically rated the services of camp and incontinence supplies as more useful than non-participants. It is possible that the difference in ratings for the camp service could be related to the timing of the survey itself. Surveys were mailed out in the summer of 2022, and people who were enrolled in the FS program in 2020 or 2021 but not in 2022 were sent the non-participant surveys. During the COVID-19 pandemic of 2020, all summer camps for people with DD in the area served by DDS were closed. Over 60% of the camps operating in 2019 did not reopen until after the summer camp season of 2021. For people enrolled in the FS program during those two years, it would have been very difficult to find any camp options for people with DD during that two-year period. The lower usefulness ratings may be explained by the lack of availability that people experienced.

It is unclear why the usefulness ratings of incontinence supplies were rated lower by non-participants than participants. It could be that people who used these services in 2020 and 2021 needed more supplies than usual, related to the closure of schools or day programs during the pandemic-related shutdowns and people with DD being home more often than usual. While the FS program allocations did increase by $500 in those two years, it is possible that their annual allowance did not cover all of the supplies they needed. This difference could also be related to the delays in receiving supplies that were happening nationwide during that period, as people across the country scrambled to find personal protective equipment and other similar supplies.

Differences in ratings of service usefulness, overall program satisfaction, or willingness to recommend the program did not significantly vary based on age, race, gender, or ethnicity of participants. This may have been due to the fact that the flexibility and opportunities for individuals and families to determine what services they need and how much to spend on them allowed people enrolled in the FS program to find something that meets their needs. Participants and non-participants with mobility, communication, and behavioral/mental health needs also rated FS services as helpful/very helpful without significant differences between people with these types of need factors.

Findings also suggested that while satisfaction and ratings of helpfulness of services were high, there were adjustments that could be made to simplify the program and therefore increase access and ease of use for participants. Several of these findings and recommendations from interviewees were incorporated into the action plan of this research study.

Finally, results of interviews clearly demonstrated that family caregivers experienced high levels of stress and financial challenges while caring for their family members with DD, and even with the FS program they still had unmet needs. Participants repeatedly indicated that they needed information about available resources, easy access to services, and that being able to make choices about what is best for them and their family were critical to their wellbeing and ability to continue to provide care. These needs must be considered by agencies that implement FS programs both now and in the future.

Action Plan

My research was aimed at understanding factors that influence why people use the FS program and that may relate to their satisfaction with the program, exploring predisposing factors (including demographics of the person), enabling factors (those that support and encourage access to services, including usefulness of services) and need factors. Data analysis identified a number of themes, which I utilized to create an action plan for next steps as part of my practical action research project.

Action Plan Description

This section describes the areas to be addressed in my action plan. There are several areas that my action plan will address and are designed in response to specific elements of my research findings and will directly address the problem of practice for this DiP. These specific areas include improving communication with people about the FS program by revising the program website, brochures, and directly calling participants, which respond to findings that indicate people do not have enough information about the FS program to use it effectively. Another specific area of the action plan includes reducing limitations on the types of equipment participants are able to access and allowing for reimbursement for purchases, which respond to the findings that participants did not have sufficient ability to direct how they used the program allowance and had to wait for purchases to be made on their behalf. Finally, the action plan specifically addresses the need for increased feedback from program participants as services are changed or decisions are made by including annual participant surveys to the ongoing administration of the program. These changes outlined in the action plan will help address the problem of practice by making the FS program a more effective, useful program that can provide some relief to people with DD and their caregivers and help eliminate the long wait for services they experience.

Improve Communication and Provide Information

Many people in the DDS FS program do not fully utilize their annual funding allotment because they don’t know what services the program offers. As such, the first objective in my action plan was to help people understand what services are available to them and how to access them.

Recommendations from several studies to help individuals and families obtain better information about services available to them included easy to understand websites and information about various programs (Bear, et al., 2020; Brown, et al., 2017; Milberger, et al., 2022). Simplified forms, use of visual aids, use of social media, and navigation programs which would connect families to others who are familiar with the program were also recommendations in related research. Therefore, the first step of my action plan was to adjust communication about available services and how to access them.

Action steps for this objective included creating resources for families enrolled in the FS program that allowed them to see where in the community they may be able to utilize their funding, simplifying printed and website materials, and establishing a process by which FS staff personally reached out to families who are new to the program or who were not utilizing their funding. The agency also recognized the need to communicate program updates with a wider audience, with the goal that previous participants and others who had never been enrolled in FS would find the services helpful and enroll or re-enroll.

Simplify Access and Increase Person-Directed Services

Programs that are person-directed (also called self-directed) allow participants to make decisions about how to spend their funding on services they want or need and from whom (National Institute on Consumer-Directed Long-Term Services, 1996). Numerous studies have demonstrated that people enrolled in person-directed programs experience many positive benefits, including higher levels of satisfaction, lower levels of unmet needs, and increased community involvement (Brown, et al., 2018; Harry et al., 2017; Schore et al., 2007). Individuals in person-directed programs appreciate the flexibility and choices that these programs offer, specifically the ability to purchase goods and services beyond hands-on assistance from a caregiver (Doty, et al., 2012; Schore et al, 2007).

Despite the support for person-centered service options for people with DD, research suggests that many of these programs still come with administrative burdens, including restrictions on how funding could be utilized (Brown, et al., 2018). Themes from the interviews echo what several studies documented: individuals with DD or their families often feel that they are not viewed as those that best understand the needs of the person enrolled in the self-directed programs (Bear, et al., 2020; Brown, et al., 2018).

The next two objectives in my action plan focused on ways to simplify access to services and increase the ability of individuals with DD and their families to direct their own services. While there are several services available in the FS program that I could have made the focus of my action plan, I chose the two services that are utilized most often by FS participants: camp and equipment. A critical part of my practical action research is to reflect on the changes that we make and then revise them as needed based on feedback and new information we receive from program participants. Future action steps will include ways to simplify additional services available through the program once these initial action steps are completed.

My second objective focuses on the purchase of equipment for people in the FS program. At the time of my research, a licensed therapist had to recommend any equipment that is purchased through the program, and the equipment had to be considered “adaptive” for FS funds to be used. For example, a child with limited mobility who cannot utilize a typical bicycle may need an adaptive three-wheeled tricycle to improve gross motor skills and encourage physical activity. A therapist would complete a lengthy form justifying the need for the item, and the request would be reviewed by a therapy manager at DDS before it could be purchased. However, because of the requirement for all equipment to be adaptive, a child with a developmental disability who needed to improve gross motor skills and increase physical activity but could utilize a typical bicycle would not be able to access FS funds for this purchase.

Feedback from families indicated that these requirements made it difficult to access equipment they need for individuals with DD. For some, finding a therapist was difficult, and they reported that therapists often struggled with the lengthy form that was required. For others, the delay caused by having DDS staff review all recommendations before items could be ordered was frustrating. Finally, families suggested that the requirement for all items to be defined as adaptive, especially given the limited annual allowance of the FS program, was unnecessary and limited their ability to make decisions that were person-centered. The FS team agreed, and thus the action plan outlined several steps to simplify this process. First, agency staff no longer review recommendations by a therapist. If an item is recommended, the therapist will complete a simplified form and the item will be ordered. Second, items that met a developmental need could be purchased within the annual allowance, giving people a more active role in determining what they need even if the items may not always be considered “adaptive” by the general public. Finally, DDS staff can meet with families who do not have a therapist to make recommendations to meet the needs of individuals in the FS program. The action steps included revising program guidelines, training staff, and communicating these changes with families.

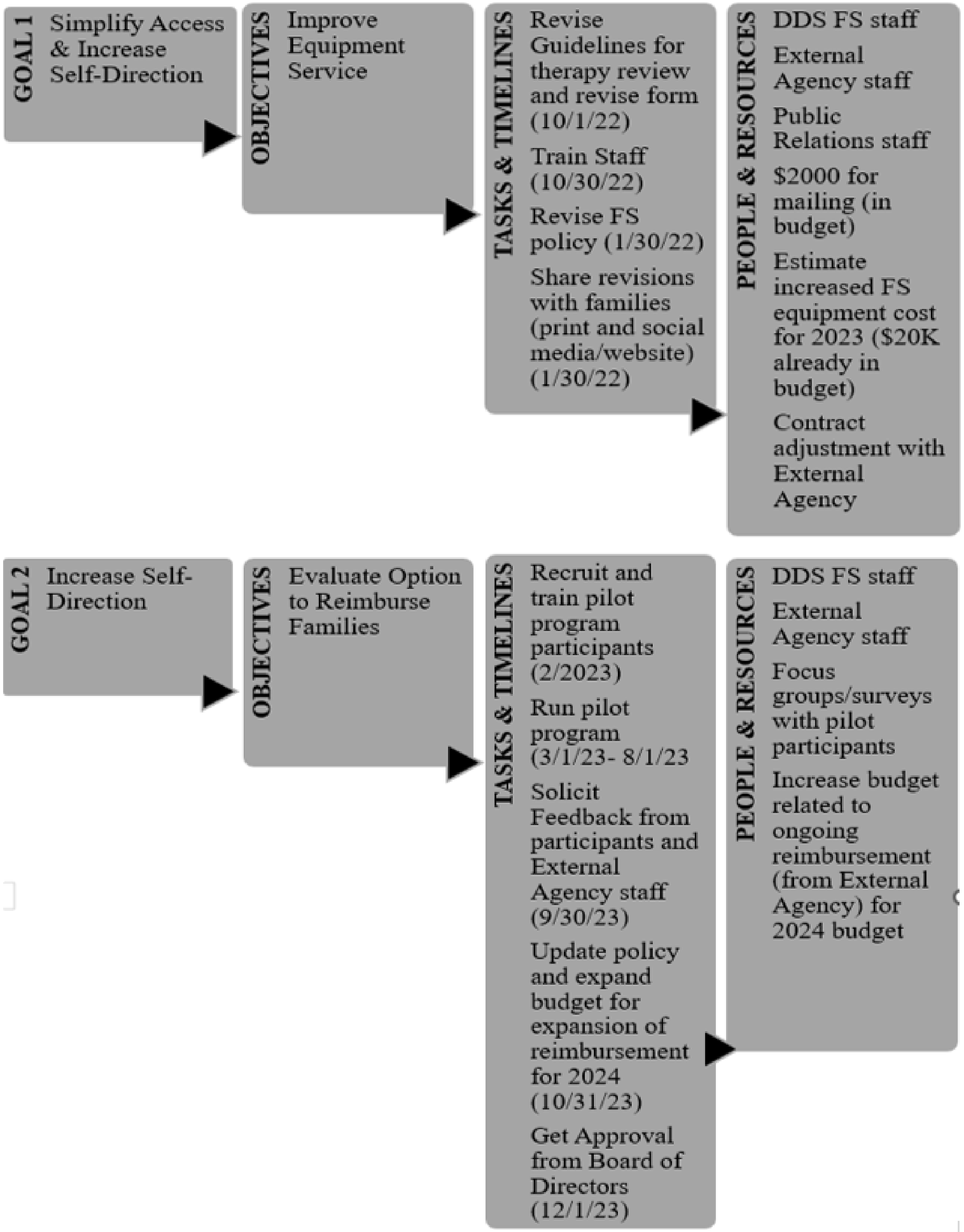
The third objective of my action plan focuses on the camp service offered through the FS program. For many years, families had to submit a request to External Agency, who administered the FS program in conjunction with DDS staff, to pay for and enroll someone with DD into a summer camp. Feedback from my research suggested that summer camp enrollment often fills up quickly for certain camps and by the time people make a request to External Agency, the camp they wanted or the weeks they needed were already full. Although not all indicated they would be able to pay upfront for a camp and be reimbursed by External Agency later, a number of families stated this would be a simple and viable option for them. One of my objectives was to create a pilot program to determine if reimbursement for camp (and eventually other services) is an option we could provide to FS participants.

Implementing this objective was especially complex because of the current fiscal structures in place at DDS. As a government agency, there are many restrictions regarding who can be a vendor and be paid by the agency (or by External Agency on behalf of DDS) which makes paying families complicated. Guidelines required that providers of services must be certified by the state, so not all camps would qualify. To work through these challenges without disrupting the camp service for thousands of people, a small pilot program was scheduled to be implemented in 2023 with the goal of expanding this option in 2024.

Ongoing Feedback

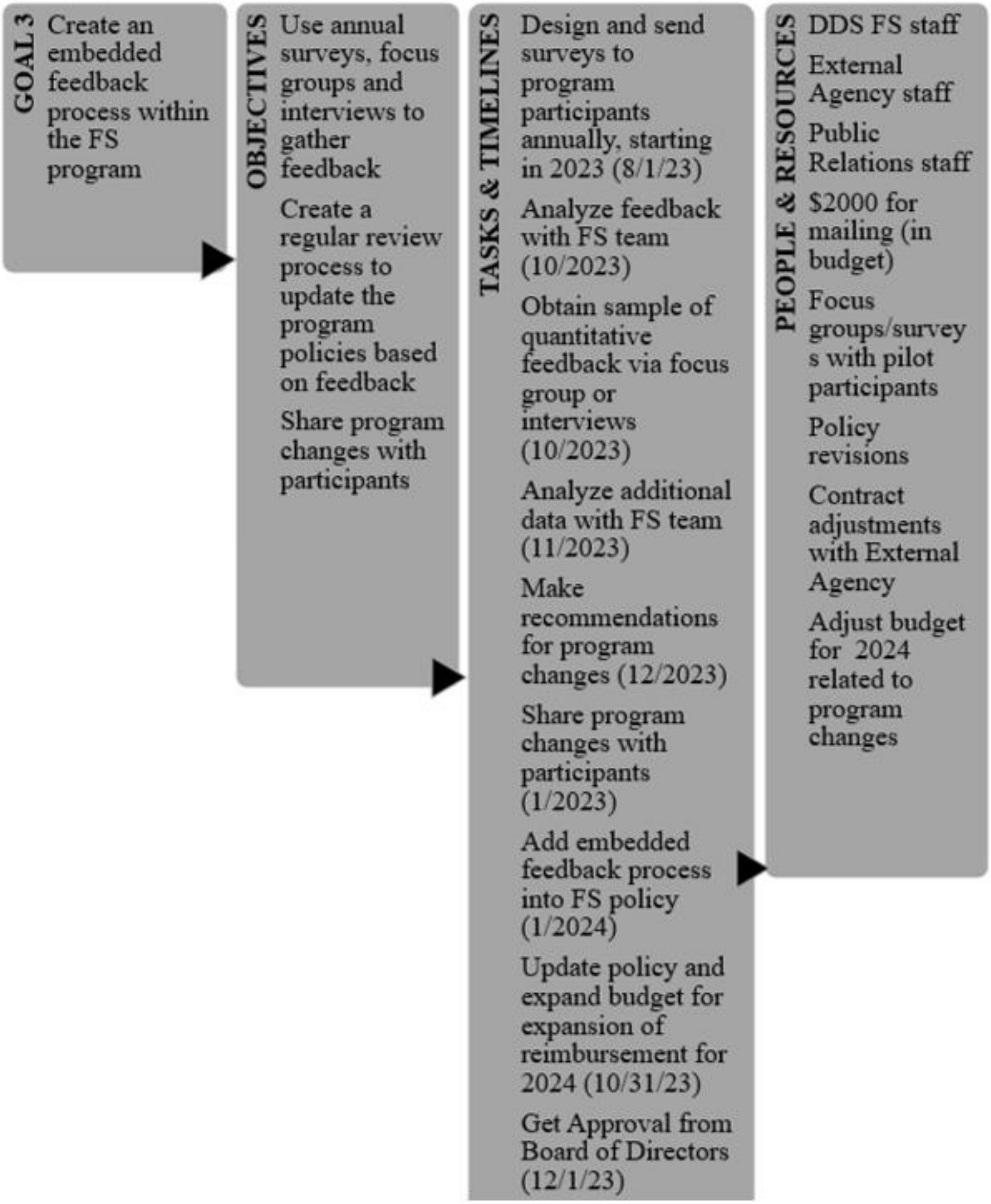
A critical component of my practical action research was to obtain ongoing feedback from FS participants about the program and services. DDS has already agreed to add an ongoing annual survey component to the program administration, whereby people enrolled in the program will receive surveys asking for feedback about the changes made to the program and usefulness of other FS services.

The action plan for the research is depicted in Figure 10 below.



GOAL 1	OBJECTIVES	TASKS & TIMELINES	PEOPLE & RESOURCES
Simplify Access & Increase Self-Direction	Improve Equipment Service	Revise Guidelines for therapy review and revise form (10/1/22) Train Staff (10/30/22) Revise FS policy (1/30/22) Share revisions with families (print and social media/website) (1/30/22)	DDS FS staff External Agency staff Public Relations staff $2000 for mailing (in budget) Estimate increased FS equipment cost for 2023 ($20K already in budget) Contract adjustment with External Agency

GOAL 2	OBJECTIVES	TASKS & TIMELINES	PEOPLE & RESOURCES
Increase Self-Direction	Evaluate Option to Reimburse Families	Recruit and train pilot program participants (2/2023) Run pilot program (3/1/23- 8/1/23 Solicit Feedback from participants and External Agency staff (9/30/23) Update policy and expand budget for expansion of reimbursement for 2024 (10/31/23) Get Approval from Board of Directors (12/1/23)	DDS FS staff External Agency staff Focus groups/surveys with pilot participants Increase budget related to ongoing reimbursement (from External Agency) for 2024 budget



GOAL 3	OBJECTIVES	TASKS & TIMELINES	PEOPLE & RESOURCES
Create an embedded feedback process within the FS program	Use annual surveys, focus groups and interviews to gather feedback Create a regular review process to update the program policies based on feedback Share program changes with participants	Design and send surveys to program participants annually, starting in 2023 (8/1/23) Analyze feedback with FS team (10/2023) Obtain sample of quantitative feedback via focus group or interviews (10/2023) Analyze additional data with FS team (11/2023) Make recommendations for program changes (12/2023) Share program changes with participants (1/2023) Add embedded feedback process into FS policy (1/2024) Update policy and expand budget for expansion of reimbursement for 2024 (10/31/23) Get Approval from Board of Directors (12/1/23)	DDS FS staff External Agency staff Public Relations staff $2000 for mailing (in budget) Focus groups/surveys with pilot participants Policy revisions Contract adjustments with External Agency Adjust budget for 2024 related to program changes

Figure 10

Action Plan

Timeline

The components of my action plan work together to improve the FS program at DDS, and individual components of the plan will be implemented at different times. Some of the work related to updating information available for FS program participants (and others, who may be interested in the FS program but who are not yet enrolled) has already begun, as have updates to FS brochures, the DDS website, and social media sites. Adjustments to the requirements for equipment purchases have also already been implemented, and people enrolled in the program were made more widely aware of these changes. The camp reimbursement pilot is planned for 2023, with the goal of a full implementation by 2024. Ongoing feedback will be obtained each year, beginning in 2023.

CHAPTER THREE

DESCRIPTION OF THE INTERVENTION

My action plan focused on three primary areas of intervention related to the DDS FS program: improve communication and provide information, simplify access and increase person-centered options that allow for self-direction of services, and gather ongoing participant feedback. These action steps were based on the findings discussed in chapter two and were informed by the principles of self-determination as previously discussed and research that shows the value of similar program to caregivers as well as people with DD (Caldwell & Heller, 2007; Freedman & Boyer, 2000; Heller et al., 2015). The goal of implementing the changes outlined in the action plan was to increase utilization of the FS program by creating a program that is more useful to individuals with DD and their caregivers.

Steps Taken

Related to the first objective to improve communication and provide information, FS staff reviewed past invoices and vendor lists to create a comprehensive list of organizations in the community where FS participants have successfully utilized funding for recreational activities and memberships. They utilized this information to create visual infographics and made changes to the FS brochure that is shared with FS families. The FS team drafted scripts for short videos on a variety of topics, including which services are available through the program, how to apply, and how to access services. The activities list, new brochure, infographic, and videos was published on the agency website and social media sites for families to reference and to inspire them to find ways to use their funding that suit their individual preferences and circumstances. The annual

FS program mailing containing these new and improved examples and a letter explaining the changes was completed in the first quarter of 2023.

The final component of increasing communication and providing information about the FS program involved having FS staff contact individuals who are newly enrolled or who are not utilizing their funding to assist them with determining what services might meet their needs. This began in Spring of 2023 and will continue as part of the ongoing administration of the program.

Steps taken related to the second objective, to simplify access and increase person-centered services that individuals and families can direct themselves related to two specific services: camp and equipment. In the Fall of 2022, the FS program policy regarding the ordering and approval process for equipment was significantly revamped to allow for greater flexibility and increased ability for individuals and their support teams to decide what they need. Additional approvals beyond a therapist recommendation were eliminated and recommendation forms were simplified, resulting in reduced time needed to order necessary equipment for families. Program brochures were updated, as was the website (including short how-to videos). These communication methods highlighted the new simplified requirements, and the availability of DDS therapists to work with a family to obtain items if the person did not have a therapist were advertised to program participants.

In the Spring of 2023, the FS team worked with External Agency to begin a pilot program to allow families to pay for camp themselves and be reimbursed, again increasing self-direction and reducing the administrative burden of waiting for another agency to register and pay for the selected camp. At the time of this writing, the pilot was ongoing, but results will be reviewed by the FS team and plans made to adjust or expand for the following camp season.

Finally, to obtain ongoing feedback from program participants, FS staff began work on a survey to be distributed to FS participants beginning the summer of 2023 asking for their input on program service options, satisfaction, and most importantly, their response to the changes to the FS program implemented between 2022 and early 2023. The FS team was also working on a timeline for sharing the survey, reviewing results and discussing the next planned improvements to the FS program, which includes annual surveys and a sample of interviews as appropriate.

Analysis of Implementation

At the time of the writing of this document, my research was in the later stages of implementation and reflection, according to Mertler’s (2014) Action Research Model. The action plan has been developed, with some steps recently implemented and others in process.

Because several action steps have been completed, I can reflect on the implementation of those items. Steps related to improving communication and providing information about the FS program were implemented as expected, with relatively few challenges. FS staff worked to revise program brochures and website information and began videos as planned. These work efforts did take more time than originally anticipated, largely due to the continued high volume of requests for FS spending until the very end of 2022 which took up most of staff capacity.

In addition, there was some initial discussion within the organization about creating a list of vendors or community locations that have accepted FS funding. The intent of this action item was to provide participants with examples of locations where they might access services, hoping that these might spark participants' own ideas about how funding could be utilized to best meet their needs. However, some staff were concerned that participants might view these examples as the only options available to them. The team eventually agreed to create the list and include a clear statement that it was not exclusive or intended to limit participants' options.

Steps related to simplifying access and increasing person-centered, self-directed services presented some challenges and unplanned consequences. First, as expected the financial controls and limitations of DDS and External Agency created a barrier to creating the pilot program for camp reimbursements for families. External Agency indicated that because of the increased work, they would need to increase their administrative fees for this pilot. Although the need for additional funding was resolved quickly and included in the DDS 2023 budget, the increased cost was not initially considered in my action plan. Also unplanned was the difficulty in finding pilot participants. While several people who were interviewed indicated interest in this option, when approached to participate in the pilot many families responded that without a definite time frame for prompt reimbursement, they would not be able to commit. This challenge required the FS staff to reach out to more potential participants than originally planned.

A consequence of implementing the action steps to simplify access to equipment was the decrease in time it took for equipment orders to be placed and shipped to FS program participants. Prior to the changes made in Fall of 2022, External Agency took an average of 17.9 days to complete equipment purchases. Following the implementation of this action step, the average was 5.2 days for a 71% decrease. This reduction was an unplanned but positive consequence, demonstrating simplified access to services for individuals with DD.

Finally, one other potential consequence of my research has been an increase in overall FS utilization by participants. In 2021, only 66% of participants used some portion of their annual funding. In 2022, this amount increased to 79% of participants utilizing the program. It is uncertain as to the reason for this increase, as many of the action plan steps were not implemented until the fall of 2022, but it is possible that these changes contributed to the increase. It is also possible that the mailing of surveys and reminder emails about the FS program related to this research impacted people's use of their funding. It will be important to monitor utilization in 2023 after all action steps are implemented to see if utilization rates continue to increase.

Because many steps of my action plan had not yet been implemented, it became even more important to identify how I would evaluate whether my action research helped resolve my problem of practice. My plan to evaluate the effectiveness of my action plan was to utilize an embedded evaluation (EMB-E) approach, as outlined in goal 3 of the action plan. This method is based on principles of continuous improvement and consists of a combination of approaches designed to examine and refine the outcomes of the action plan (Giancola, 2021). There is a dynamic and cyclical nature inherent in EMB-E in which each step of the evaluation process influences the other steps, allowing for the work to occur simultaneously on short- and long- term objectives (Giancola, 2021). EMB-E requires the collaboration of key stakeholders (in this case, including program participants and program staff), wherein feedback from the stakeholders helps DDS assure that the program is working for participants (Barry et al., 2018; Giancola, 2021). An embedded evaluation approach provides especially valuable feedback not only about whether a program improvement or design change "worked" but why it did or did not work and what changes may still be helpful (Barry et al., 2018). While this approach is often used for new programs, it can be quite effective for established programs such as the FS program, prompting an agency to clarify aspects of program implantation and revisit program goals to foster buy-in from stakeholders (Giancola, 2021).

Meaning making/interpretation

The action plan is grounded in the results of my study. However, it is important to consider the larger meaning of this research within the best practices related to DD services. My overall research framework was to use a phenomenological approach in order to better understand the lived experiences of people enrolled in the FS program and their caregivers. Choosing this approach was intentional and rooted in perhaps the most important principles related to DD services: self-direction and person-centered planning. Without the direct input from people served by the program, any adjustments to the program would be ineffective and perfunctory.

My research framework also utilized Andersen's Behavioral Model (1995) to better understand whether specific characteristics of participants influenced satisfaction on a macro level. This research did not find that there was a significant difference in the ratings of helpfulness of services among people with communication, mobility, or behavioral/mental health needs compared to people without those needs. Had there been differences between one or all these groups, more exploration and research would be appropriate. Similarly, the research did not find there were significant differences in satisfaction between groups. If I had found those differences, it would have been important to further research what factors influenced those differences in order to address them and increase utilization within those groups.

Results of action/intervention/change processes

At the time of this publication, I could not fully implement the action plan and report on results regarding effectiveness of this action research project. I believe that the action plan is promising and could significantly improve the FS program at DDS. I anticipate that implementation of the action plan will result in an increased utilization of FS services, but this will have to be evaluated following full implementation and time during which participants will utilize their funds over a program year. I also expect high levels of satisfaction in response to the program changes that were made in late 2022 and early 2023. Anecdotally, several participants have indicated they are pleased with the changes in their conversations with FS program staff but data from the surveys sent in the summer of 2023 will need to be reviewed carefully by the FS team to determine if this is the case.

Analysis of Organizational Change and Leadership Practice

The practices in my action plan to drive organizational change and the leadership principles I have employed are a combination of several theories studied throughout the doctoral program as discussed below. I expect my action plan to lead to sustainable changes at DDS because the changes being made to the FS program will better serve people with DD and their family caregivers in line with the mission of the organization.

Type of organizational change

My action plan focuses on emergent change, which is responsive to the changing needs of stakeholders. As indicated in the action plan, ongoing feedback from program participants will be built into administration of the FS program which will allow the agency to reflect on and adjust to the needs of the people served (Olive, 2020). The FS staff will also play a central role in reviewing feedback, suggesting further adjustments to program services, and working with individuals and caregivers to determine the best ways to make those changes.

The rationale for a given organization change impacts the likelihood of success of that change (Hyde, 2012). In this case, the DDS's strategic plan outlines short- and long-term goals to provide excellent quality services to people with DD in the most inclusive environment possible, and to provide services in a person-centered and equitable manner. Because the action plan steps I developed directly support those agency goals, I expect this research to create sustainable change at DDS.

The embedded evaluation method I am utilizing requires ongoing feedback from stakeholders (including program participants, family caregivers and staff) and as such increases the likelihood that the FS program will continue to evolve in ways that support people with DD to have access to services they need and want, rather than those conceived by agency administrators alone. Including FS staff in the cycle of feedback and revisions to the program increases the likelihood that staff will embrace the changes and work to make the program one that is truly person-centered. Research supports the idea that employees' feelings directly affect their work performance, whether it is in terms of their attitudes and motivations or related to policies they are expected to enact

(Hiekischova, 2019; Tichnor-Wagner, et al., 2019). When staff feel disconnected from the policies they must enact, the likelihood of successful implementation of those policies decreases (Lipsky, 2010). Even if they are unable to articulate the assumptions they have about their work reality, employee assumptions impact the values, or goals/characteristics within the culture that have worth and that guide employee behavior and emotions (Hatch, 2018). Connecting staff to program changes and policies by having them provide input and create solutions to challenges within the FS program is likely to have a positive, long-lasting effect on staff willingness to be creative and flexible when administering the program.

It was also important to consider these organizational changes through the lens of building sustainable, equity-oriented change within DDS. Equity-oriented organizational change is part of a continuous improvement cycle and is both a process and an outcome rather than solely an objective to be achieved. Bonnycastle (2011) outlines a “Relational Illustrative Model" which focuses on a social justice continuum. At one end of the continuum is social oppression, in which a group or system of privilege exploits or dominates another group. At the other end of the continuum is social equity, where all individuals have equal worth that is demonstrated through policy decisions (Bonnycastle, 2011). Through the lens of organizational change, an agency works along the continuum away from social oppression, creating equity in systems and opportunities for all participants. Critical to success is the recognition and representation of different identities within the organization and the commitment to value the contribution of each person. In terms of DDS’s current status,this means moving even further in a direction in which the agency actively involves people with DD from a variety of racial and ethnic backgrounds in decision making about services available to them. Changing the FS program to allow for more self-direction has the potential to increase opportunities for self-direction in other program areas, and to allow for further equity for the people supported by DDS. To have a voice in the organization, people with disabilities and those from historically marginalized backgrounds must be part of the embedded evaluation process as outlined in my action research steps.

Reflection on leadership practices

Throughout this project, I was intentional in my interactions with both FS participants or caregivers and FS staff to regularly communicate the purpose of the research and the action steps as they were created. The importance of developing FS services that were person-centered and useful to people with DD and their families could not be understated. Quinn (2011) talks about the use of discretionary energy, stating that people only have a certain amount of energy that they bring to a given task, and to get them to use that energy is to connect them to their purpose. Quinn goes as far as to state that a primary responsibility of a leader is to help people make this connection (2011). The idea of connecting people to a purpose resonated with me as we worked through FS program changes, and this is a leadership practice that I will continue to utilize going forward.

My other primary takeaway in terms of leadership practice was to be comfortable with the unknown, and to respond to situations with flexibility. I had to be flexible several times throughout data collection, including developing two different surveys each with two different formats (electronic and paper) and in terms of conducting interviews. When it was difficult to obtain the number of non-participant surveys I expected, I adjusted. I often had to be flexible during the interviews as well, rephrasing questions, engaging in conversations with additional family members who joined interviews, and in some cases, building in breaks during the actual interviews. This flexibility allowed me to gather the detailed and rich data described in earlier sections of this document. When I worked with FS staff to discuss implementing the action plan steps, I had to be flexible when I encountered challenges (like additional funding for External Agency and limited volunteers for the reimbursement pilot). Flexibility is already a trait I employ in my work, but when I thought about it as a leadership principle I found I was able to encourage and promote flexible thinking in the stakeholders with whom I engaged in this project, and that their responses were overwhelmingly positive rather than frustrated when obstacles arose.

Implications for Practice and Future Research

Not only does this research have significant practical implications for DDS, it can have profound impact on the DD system in the Midwest U.S. and elsewhere. In the state where DDS operates, over 60 organizations administer FS programs. These research findings regarding usefulness of various services, strong desire for self-direction, and potential administrative burdens provide a starting point for these organizations to evaluate and improve their own FS programs. These agencies should also utilize the principles of embedded evaluation and actively include program participants in decision making regarding their FS programs to further support self-direction opportunities.

Future research should consider ways to allow for even greater person-centered, self-directed options in FS programs. As previously mentioned, some states have operated cash and counseling programs which allow individuals with disabilities to receive cash subsidies that they can utilize to meet any of their service needs by purchasing them directly rather than through an agency. Given the findings of my research and the limited allowance of many FS programs, it could be beneficial to explore how to adjust FS programs to further eliminate administrative controls by using some of the principles of these cash and counseling programs.

There are a few limitations of this study that could be addressed by future research. First, this study had a low response rate for non-participants. Although not unexpected, the response rate limits the conclusions that can be drawn from this data. As such, future research or adjustments to agency practices could explore satisfaction and reasons why people exit FS programs as they leave, rather than months or years later. In addition, the collection of race and ethnicity information in this study utilized categories established for the US census, and therefore collected ethnicity information separate from race. This made it difficult to determine whether people who identify as hispanic also chose “white,” “other,” or some other category as their racial identity, and therefore identify any potential impact ethnicity may have on ratings of satisfaction or usefulness of services. Future research should consider this in survey design.

Conclusion

Agencies that do not administer similar self-directed programs should consider not only the benefits of FS programs as cited in this research, but those from a growing body of research discussed previously in this paper. This research project supports the idea that even a relatively small annual funding allowance provides relief and support to family caregivers of individuals with DD who are critical to supporting people with DD throughout their lives. Considering the current financial strain on the entire DD system, DD service agencies and government entities must consider FS programs as a viable and cost-effective service option.

REFERENCES

Aday, L. A., & Andersen, R. M. (1974). A framework for the study of access to medical care. *Health Services Research*, 9, 208-220. https://search-ebscohost-com.libproxy.udayton.edu/login.aspx?direct=true&db=mnh&AN=4436074&site=eds-live

Agosta, J. M., Bradley, V. J., Human Services Research Inst., B. M., & National Association of State Mental Retardation Program Directors, A. V. (1985). *Family Care for Persons with Developmental Disabilities: A Growing Commitment*. https://eric.ed.gov/?id=ED259498

Agosta, J., & Melda, K. (1995). Supporting families who provide care at home for children with disabilities. *Exceptional Children*, *62*, 271-282. https://journals.sagepub.com/doi/pdf/10.1177/001440299606200308

Allard, M. A., Gottlieb, A., & Hart, D. (1993). *Impact study of the family cash assistance project: Year three results*. Prepared for the Massachusetts Developmental Disabilities Council. Waltham, MA: The Shriver Center.

Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M. & Regan, J. (2018). Family and individuals needs for disability supports (v.2) community report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. https://r.search.yahoo.com/_ylt=AwrEeB0mLiJibAYAHxMPxQt.;_ylu=Y29sbwNiZjEEcG9zAzEEdnRpZAMEc2VjA3Ny/RV=2/RE=1646436006/RO=10/RU=https%3a%2f%2fthearc.org%2fwpcontent%2fuploads%2fforchapters%2fFINDS_report-2017-FINAL-VERSION.pdf/RK=2/RS=qjW8z_xxIM8MCQZmgKV6z5jDeGk-

Anderson, L. L., Larson, S. A., MapelLentz, S. & Hall-Lande, J. (2019). A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000. *Intellectual and Developmental Disabilities, 57*(5), 421-438. https://search-ebscohost-com.libproxy.udayton.edu/login.aspx?direct=true&db=eric&AN=EJ1231255&site=eds-live

Andersen, R. M. (1968). *Behavioral model of families' use of health services*. Research Series No. 25. Chicago: Center for Health Administration Studies, University of Chicago.

Andersen, R. M. (1995). Revisiting the behavioral-model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1-10. https://www-jstor-org.libproxy.udayton.edu/stable/2137284

Andersen, R. M. (2008). National health surveys and behavioral model of health services use. *Medical Care, 46*(7), 647-653. doi:10.1097/MLR.0b013e31817a835d

Arno, P. (2002). Well-being of caregivers: The economic issues of caregivers. In T. McRae (Chair), *New caregiver research*. Symposium conducted at the annual meeting of the American Association of Geriatric Psychiatry, Orlando, Florida.

Arno, P.S., Levine, C., & Memmott, M. M. (199). The economic value of informal caregiving. *Health Affairs, 18,* 182- 188. https://doi-org.libproxy.udayton.edu/10.1377/hlthaff.18.2.182

Avedian, A. (2014, Oct 15). *Survey Design* [Power Point Slides]. Harvard Law School.

http://hnmcp.law.harvard.edu/wp-content/uploads/2012/02/Arevik-Avedian-Survey-Design-PowerPoint.pdf

Barry, D., Kimble, L. E., Nambiar, B., Parry, G., Jha, A., Chattu, V.K., Massoud, M. R., & Goldmann, D. (2018). A framework for learning about improvement: embedded implementation and evaluation design to optimize learning. *International Journal for Quality in Health Care: Journal of the International Society for Qualkity in Health Care, 30*(suppl_1), 10-14. https://doi-org.libproxy.udayton.edu/10.1093/intqhc/mzy008

Bear, A., Drew, C., Zuckerman, K., & Phelps, R. A. (2020). Understanding barriers to access and utilization of developmental disability services facilitating transition. Journal of Developmental and Behavioral Pediatrics, 41(9), 680-689. DOI: 10.1097/DBP.0000000000000840

Berger, R. (2015). Now I see it, now I don't: Researcher s position and reflexivity in qualitative research. *Qualitative Research*, *15*, 219–234. https://doi-org.libproxy.udayton.edu/10.1177/1468794112468475

Biber, S. H. (2016). *The practice of qualitative research: Engaging students in the research process* (3rd ed.). SAGE Publications, Inc.

Bishop, L. (2021, September 25). Developmental Disability facing 'crisis' labor shortage.

Dayton Daily News. https://www.daytondailynews.com/local/developmental-disability-services-facing-crisis-labor-shortage/GZNLC4QBMNDPZFX7DAYLZ2NRM4/

Braddock, D., Hemp, R., Rizzolo, M. C., Coulter, D., Haffer, L., & Thompson, M.

(2005). The state of the states in DD 2005: Preliminary report. University of Colorado, Department of Psychiatry and Coleman Institute of Cognitive Disabilities. https://www.researchgate.net/publication/305905244_The_State_of_the_States_in_Developmental_Disabilities_2005

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E.S., Haffer, L., Lulinski-Norris, A., & Wu, J. (2013). The state of the states in developmental disabilities: 201: The Great Recession and its aftermath. Washington, DC: American Association on Intellectual and Developmental Disabilities. http://dx.doi.org/10.1097/JGP.0b013e3181a65187

Braddock, D.L., Hemp, R.E., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the Great Recession.* Washington, DC: American Association on Intellectual and Developmental Disabilities. https://www.researchgate.net/publication/318249793_The_State_of_the_States_in_Intellectual_and_Developmental_Disabilities/link/59c008d8aca272aff2e2045a/download

Braddock, D.L., Hemp, R.E., Tanis, E. S., Wu, J. & Haffner, L. (2017). *The state of the states in intellectual and developmental disabilities: 2017.* Washington, DC: American Association on Intellectual and Developmental Disabilities. https://www.researchgate.net/publication/320962803_The_State_of_the_States_in_Intellectual_and_Developmental_Disabilities_2017

Brown, M., Harry, M., & Mahoney, K. (2018). “It’s Like Two Roles We’re Playing”:

ParentPerspectives on Navigating Self-Directed Service Programs with Adult Children with Intellectual and/or Developmental Disabilities. *Journal of Policy & Practice in Intellectual Disabilities*, *15*(4), 350–358. https://doi-org.libproxy.udayton.edu/10.1111/jppi.12270

Burke, M. M. & Heller, T. (2017). Disparities in unmet service needs among adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 30*, 898-910. https://doi-org.libproxy.udayton.edu/10.1111/jar.12282

Burke, M. M., Lulinski, A., Jones, J., Gallus, K. (2018). Chapter Five - A Review of Supports and Services for Adults with Intellectual and Developmental Disabilities (IDD) and Their Families in the United States: Past and Present Contexts Impacting Future Research, Practice and Policy. *International Review of Research in Developmental Disabilities, [s. l.]*, v. 54, p. 137–176. https://doi-org.libproxy.udayton.edu/10.1016/bs.irrdd.2018.07.005

Caldwell, J. (2006). Consumer-directed supports: economic, health and social outcomes for families. *Mental Retardation*, *44*(6), 405-417. http://dx.doi.org/10.1352/0047-6765(2006)44{405:CSEHAS}2.0.CO;2

Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services

in a consumer-directed family support programme. *Journal of Intellectual Disability Research*, 47, 352-366. http://pascal-francis.inist.fr.libproxy.udayton.edu/vibad/index.php?action=search&terms=14878336

Caldwell, J., & Heller, T. (2007). Longitudinal outcomes of a consumer-directed program

supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities, 45*(3), 161-173. http://dx.doi.org/10.1352/1934-9556(2007)45[161:LOOACP]2.0.CO;2

Carr-Chellman, D. (2020). Identifying goals and objectives. [PowerPoint slides]. University of Dayton. Communication and Community Engagement. Digital Campus. https://digitalcampus.instructure.com/courses/6438/pages/lecture-slides?module_item_id=630977

Charmaz, K. (2006). *Constructing grounded theory : a practical guide through qualitative analysis*. Sage Publications. https://search-ebscohost-com.libproxy.udayton.edu/login.aspx?direct=true&db=cat02507a&AN=ohiolink.b24785755&site=eds-live

Christ, T. W. (2010). Teaching Mixed Methods and Action Research: Pedagogical, Practical, and Evaluative Considerations. In A. Tashakkori & C. Teddlie (Eds.), *SAGE Handbook of Mixed Methods in Social and Behavioral Research* (pp. 643–676). Second edition. Los Angeles and London: Sage Publications.

Creswell, J., & Guetterman, T. (2019). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (6th ed.). Pearson.

Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and Conducting Mixed Methods Research* (3rd ed.). Sage.

Developmental Disabilities Services (n.d.). *About us/Mission. (anonymized).*

Developmental Disabilities Services (n.d.). *Family Supports Program. (anonymized).*

Eiken, S., Sredl, K., Burwell, B., & Woodward, R. (2017). Medicaid expenditures for long-term services and supports (LTSS) in FY 2015. Cambridge, MA: Truven Health Analytics. https://www.appliedselfdirection.com/sites/default/files/LTSS%20Expenditures%20FFY%202015.pdf

Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities, 51*(5), 333-348. http://pascal-francis.inist.fr.libproxy.udayton.edu/vibad/index.php?action=search&terms=28039910

External Agency (n.d.). *Family Supports/DDS. (anonymized).*

Factor, A., Heller, T., Janicki, M. (2015, Mar). *Bridging the Aging and Developmental Disabilities Service Networks: Challenges and Best Practices*. Institute on Disability and Human Development, University of Illinois at Chicago. https://www.aucd.org/docs/publications/bridging_aging_dd_2012_0419.pdf

Freedman, R. I., & Boyer, N. C. (2000, Feb). The Power to Choose: Supports for families

caring for individuals with developmental disabilities. *Health & Social Work, 25*(1), 59 - 68. https://doi.org/10.1093/hsw/25.1.59

Friedman, C. (2017). A national analysis of Medicaid home and community based waivers for people with intellectual and developmental disabilities: FY 2015. *Intellectual and Developmental Disabilities, 53(5)*, 323-328. https://doi-org.libproxy.udayton.edu/10.1352/1934-9556-55.5.281

Gelberg, L., Andersen, R. M., & Leake, B. D. (2000). The Behavioral Model for Vulnerable Populations: application to medical care use and outcomes for homeless people. *Health Services Research*, *34*(6), 1273–1302. https://pubmed-ncbi-nlm-nih-gov.libproxy.udayton.edu/10654830/

Harry, M. L., Mahoney, K. J., Mahoney, E. K., & Shen, C. (2017). The Cash and Counseling model of self-directed long-term care: Effectiveness with young adults with disabilities. *DISABILITY AND HEALTH JOURNAL*, *10*(4), 492–501. https://doi-org.libproxy.udayton.edu/10.1016/j.dhjo.2017.03.001

Havercamp, S. M., Krahn, G. L., Larson, S. A., Fujiura, G., Goode, T. D., Kornblau, B. L., & the National Health Surveillance for IDD Workgroup (2019). Identifying People With Intellectual and Developmental Disabilities in National Population Surveys. *Intellectual and Developmental Disabilities, 57*(5), 376-389. https://doi-org.libproxy.udayton.edu/10.1352/1934-9556-57.5.376

Heller, T. & Caldwell, J. (2005). Impact of a consumer-directed family support program on reduced out-of-home institutional placement. *Journal of Policy and Practice in Intellectual Disabilities, 2*, 63 - 65. http://dx.doi.org/10.1111/j.1741-1130.2005.00010.x

Heller, T. & Factor, A. (1993). Aging family caregivers: Support resources and changes in burden and placement desire. *American Journal on Mental Retardation, 98*, 417-426.http://pascal-francis.inist.fr.libproxy.udayton.edu/vibad/index.php?action=search&terms=3791669

Heller, T., Gibbons, H. M., Fisher, D. (2015). Caregiving and Family Support

Interventions: Crossing Networks of Aging and Developmental Disabilities. Intellectual and Developmental Disabilities, 52(5), 329-345. https://doi-org.libproxy.udayton.edu/10.1352/1934-9556-53.5.329

Heller, T., Miller, A. B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with disabilities. *Family Relations, 48,* 419-427. https://doi-org.libproxy.udayton.edu/10.2307/585250

Hesse-Biber, S.N. (2017). *The practice of qualitative research* (3rd edition). Sage Publications.

Hewitt, A., & O'Nell, S. (1998). *People Need People: The Direct Service Workforce*. Impact, 10(4), Minnesota Univ., Minneapolis. Inst. on Community Integration. https://files.eric.ed.gov/fulltext/ED416635.pdf

Holmes, A.G. (2020). Researcher Positionality: A Consideration of Its Influence and Place in Qualitative Research. A New Researcher Guide. *Shanlax International Journal of Education, 8*(4), 1-10. https://files.eric.ed.gov/fulltext/EJ1268044.pdf

Institute for Community Integration (2018). The Direct Support Workforce: A Crisis or Serious Systems Flaw? https://nisonger.osu.edu/wp-content/uploads/2018/05/Hewitt-Nisonger-5.24.18-handout-version.pdf

Ivankova, N. (2017). Applying mixed methods in community-based action research: A framework for engaging stakeholders with research as means for promoting patient-centeredness. *Journal of Nursing Research, 22*, 282-294. doi:10.1177/1744987117699655

Ivankova, N., Creswell, J. W., & Stick, S. L. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *Field Methods, 18*(1), 3–20. https://doi-org.libproxy.udayton.edu/10.1177/1525822X05282260

Ivankova, N. & Wingo, N. (2018). Applying Mixed Methods in Action Research: Methodological Potentials and Advantages. *American Behavioral Scientist, 62*(7) 978-997.

Jaskulski, T. & Ebenstien, W. (Eds). (1996). *Opportunities for Excellence: Supporting the*

Frontline Workforce. Washington, D.C.: President's Committee on Mental Retardation, U.S. Department of Health and Human Services.

Kenny, M., & Fourie, R. (2014). Tracing the history of grounded theory methodology: From formation to fragmentation. The Qualitative Report, 19(103), 1-9. https://search-ebscohost-com.libproxy.udayton.edu/login.aspx?direct=true&db=a9h&AN=100293717&site=eds-live

Krahn, G. L., Fox, M.H., Campbell, V. A., Ramon, I., & Jesien, G. (2010). Developing a health surveillance system for people with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities, 7*(3), 155-166. doi:10.1111/j.1741-1130.2010.00260.x

Kosciulek, J. F. (1999). The consumer-directed theory of empowerment. *Rehabilitation Counseling Bulletin, 42*(3), 196-213. https://eds-p-ebscohost-com.libproxy.udayton.edu/eds/detail/detail?vid=3&sid=fa4f4ad0-f310-40c5-b1e1-

009f72c2be83%40redis&bdata=JnNpdGU9ZWRzLWxpdmU%3d#AN=1882524&db=pbh

Larson, S.A., Eschenbacher, H. J., Anderson, L.L, Taylor, B., Pettingell, S., Hewitt, A.,…Bourne, M.L., (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities; Status and trends through 2016. *Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.* https://files.eric.ed.gov/fulltext/ED598171.pdf

Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation, 106*(3), 231-252. http://pascal-francis.inist.fr.libproxy.udayton.edu/vibad/index.php?action=search&terms=1024379

Mansell, J. (2006). Deinstitutionalization and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disabilities,* 31(2), 65-76. https://eds-p-ebscohost-com.libproxy.udayton.edu/eds/pdfviewer/pdfviewer?vid=34&sid=c13d5401-bec0-4c49-a18d-dcf4cd25028f%40redis

Mcdonald, K., & Patka, M. (2012). “There is No Black or White”: Scientific Community

Views on Ethics in Intellectual and Developmental Disability Research. *Journal of Policy & Practice in Intellectual Disabilities*, *9*(3), 206–214. https://doi-org.libproxy.udayton.edu/10.1111/j.1741-1130.2012.00348.x

Mertler, C. A. (2020). Action research: improving schools and empowering educators (Sixth edition.). SAGE Publications, Inc.

Midwest Agency (n.d). *News.* (*anonymized*)

Milberger, S., Marsack-Topolewski, C., Janks, E., Anderson, N., Bray, M., & Samuel, P. S. (2022). Evaluating the Benefits of a Family Support Program on the Health and Well-Being of Aging Family Caregivers of Adults with Intellectual and Developmental Disabilities. *Journal of Gerontological Social Work*, 1–20. https://doi-org.libproxy.udayton.edu/10.1080/01634372.2022.2110347

Milner IV, H. R. (2007). Race, Culture, and Researcher Positionality: Working through Dangers Seen, Unseen, and Unforeseen. *Educational Researcher*, 36(7), 388-400. doi:10.3102/0013189X07309471

National Institute on Consumer-Directed Long-Term Services. (1996). Principles of consumer-directed home and community-based services. Washington, DC: The National Council on the Aging.

Neely-Barnes S.L., Marcenko M.O., & Weber L. (2008). Community-based, consumer-directed services: differential experiences of people with mild and severe intellectual disabilities. *Social Work Research*, *32*(1), 55–64. https://doi-org.libproxy.udayton.edu/10.1093/swr/32.1.55

Olive, J. (2020). *Using Evaluation Results* [PowerPoint presentation]. 2UD.

https://2ud.educationonline.udayton.edu/ap/courses/993/sections/c778f6af-3713-4ea1-9560-c734064ce2b2/coursework/module/228a0fc3-ccb5-41b9-ae9f-1d35222c00e6/segment/b6a5db55-e219-4c9e-a4dc-d4cb567b2cae

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and policy in mental health*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Peterson, R. (2019, September 10). Staff Shortage Challenges Disability Community. *Post-Bulletin.* https://www.postbulletin.com/newsmd/staff-shortage-challenges-disability-community

State Department of Medicaid HCBS Waivers (n.d.). *HCBS Waivers. (anonymized)*

Parish, S., Pomeranz-Essley, A., & Braddock, D. (2003). Family Support in the United States: Financing trends and Emerging Initiatives. *Mental Retardation*, *41*, 174-187. https://doi-org.libproxy.udayton.edu/10.1352/0047-6765(2003)41<174:FSITUS>2.0.CO;2

Phillips, K. A., Morrison, K. R., Andersen, R., & Aday, L. A. (1998). Understanding the context of healthcare utilization: Assessing environmental and provider-related variables in the behavioral model of utilization. *Health Services Research*, *33*(3), 571-596. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1070277/pdf/hsresearch00027-0142.pdf

PHI National (n.d.). *News* https://www.phionational.org/news

Plano Clark, V. L., & Ivankova, N. (2016). *Mixed Methods Research: A Guide to the*

Field. Sage.

Powers, L. E., Sowers, J., & Singer, G. H. (2006). A Cross-Disability analysis of person-directed, long-term services. *Journal of Disability Policy Studies, 17*(2), 66-76. https://doi-org.libproxy.udayton.edu/10.1177/10442073060170020301

Prouty, R., Smith, G., G., & Lakin, K. C. (2005). *Residential services for persons with developmental disabilities: Status and trends through 2004.* Minneapolis: University of Minnesota, Research and Training Center on Community Living/Institute on Community Integration. https://rtc.umn.edu/docs/risp2004.pdf

Quinn, R.E. (2011). *The positive organization.* Berrett-Koheler Publishers, Inc.

Rizzolo, M., Hemp, R., & Braddock, D. (2006, February). Family Support Services in the United States. Minneapolis: University of Minnesota, Research and Training Center on Community Living. *Policy Research Brief, 17*(10), 1-11. https://doi-org.libproxy.udayton.edu/10.1352/1934-9556-47.2.152

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L.,

Craig, E. M., Gomez, S. C., Lachapelle, Y., Luckasson, R., Reeve, A., Shogren, K. A., Snell, M. E., Spreat, S., Tasse´, M. J., Thompson, J. R., Verdugo-Alonso, M. A., Wehmeyer, M. L., & Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of supports (11th edition)*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schore, J., Foster, L., & Phillips, B. (2007). Consumer enrollment and experiences in the Cash and Counseling program. *Health Services Research*, *42*(1 Pt 2), 446–466. https://doi-org.libproxy.udayton.edu/10.1111/j.1475-6773.2006.00679.x

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis : theory, method, and research*. SAGE.

Stones, M., McMillan, J. (2010). Payment for participation in research: a pursuit for the poor? *Journal of Medical Ethics*, 36(1), 34- 36. https://www-jstor-org.libproxy.udayton.edu/stable/20696713

Swaine, J. G., Parish, S. L., Igdalsky, L., & Powell, R. M. (2016). Consumers' and workers' perspectives about consumer-directed services in the United States. *Disability and Health Journal*, *9*(3), 464–471. https://doi-org.libproxy.udayton.edu/10.1016/j.dhjo.2016.01.002

Trent, J. W., Jr. (2017). *Inventing the feeble mind : a history of intellectual disability in the United States* (Second edition). Oxford University Press.

Walliman, N. (2011). *Research Methods: The basics.* Routledge.

Wiener, J. M., Anderson, W. L., Khatutsky, G. (2007). Are consumer-directed home care

beneficiaries satisfied? Evidence from Washington state. *Gerontologist, 47*(6). http://gerontologist.gerontologyjournals.org/cgi/content/abstract/47/6/763

Williams, M. E., Wheeler, B. Y., Linder, L., Jacobs, R. A. (2017). *Evolving definitions of Autism and Impact on Eligibility for Developmental Disability services: California case example.* Intellectual and Developmental Disabilities (55)3, 192-209. http://dx.doi.org.libproxy.udayton.edu/10.1352/1934-9556-55.3.192

Willis, J.W. (2007). *Foundations of Qualitative Research Interpretive and Critical Approaches.* SAGE Publications.

Zimmerman, S. (1984). The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. *Family Relations, 33*, 105-118. https://doi-org.libproxy.udayton.edu/10.2307/584595

APPENDIX A

Invitation To Participate In Research

Surveys and Interviews

Research Project Title: Exploring the value of Family Supports Programs (draft)

You have been asked to participate in a research project conducted by Amber Gibbs from the University of Dayton, in the Department of Education and Health Sciences.

The purpose of the project is: identify which Family Supports program services are most useful to individuals and families and identify factors that influence application and utilization of the program.

You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

- Your participation in this research is voluntary. You have the right not to answer any question and to stop participating at any time for any reason. Answering the questions will take about 10 minutes.
- You will not be compensated for your participation.
- All of the information you tell us will be confidential.
- If this is a recorded interview, only the researcher and faculty advisor will have access to the recording and it will be kept in a secure place.
- If this is a written or online survey, only the researcher and faculty advisor will have access to your responses. If you are participating in an online survey: We will not collect identifying information, but we cannot guarantee the security of the computer you use or the security of data transfer between that computer and our data collection point. We urge you to consider this carefully when responding to these questions.
- I understand that I am ONLY eligible to participate if I am over the age of 18.

Please contact the following investigators with any questions or concerns:

Amber Gibbs, Gibbsa3@udayton.edu, Phone Number:216-736-2660
Aryn Baxter, Ph.D., ABaxter1@udayton.edu, Phone Number: 585.704.0684

If you feel you have been treated unfairly, or you have questions regarding your rights as a research participant, please email IRB@udayton.edu or call (937) 229-3515.

APPENDIX B

Letter from DDS to Research Participants

Dear [NAME]:

Thank you for being a part of the Developmental Disabilities Services Family Supports Program!

It is important to us at DDS to support families as they care for their loved ones with developmental disabilities. While we partner with External Agency to help us administer the program, the Family Support program is completely funded by DDS to help individuals access services that might be helpful to them.

Our goal is to provide high-quality supports to people with developmental disabilities, and we are always looking for ways we can improve. We are partnering with a University of Dayton Doctoral student to conduct research on our Family Supports Program, and we need your input! We would like you to complete a short survey about your experience with DDS's Family Supports Program.

Important information about the survey:

- Whether or not you complete the survey DOES NOT affect your participation in the Family Supports Program.
- Your responses will anonymous, so you can feel comfortable giving us honest and candid feedback about the program.
- At the end of the survey, you will be able to enter a drawing to win one of ten (10) $50 gift cards. Gift card winners will be drawn on June 6 and June 7, 2022. Winners will be notified by email first, and then by phone. If you are completing the survey on paper, **please be sure to mail the survey and entry form back by Wednesday, June 1, 2022.**

We are also looking for volunteers to participate in a follow-up interview, where you will be able to give us even more feedback about the Family Supports program. If you are interested in participating in an interview, please complete the contact card included in this mailing and return it to us by June 1, 2022.

If you prefer to complete your survey and enter the drawing for a gift card electronically, you can do so by going to this address: XXX or scanning this QR code (code here).

Thank you for giving us your valuable feedback about Developmental Disabilities Services' Family Supports Program. We look forward to hearing what aspects of the program are most helpful to you and what can be improved!

Sincerely,
CEO, Developmental Disability Services

APPENDIX C

FS Participant Survey

1. How did you hear about Developmental Disability Services's Family Supports Program? (SELECT ONE)
   - Friend or another parent
   - DDS or Early Intervention staff
   - School
   - Community or Support Agency (describe)
   - DDS website
   - Flier, letter or mail from Cuyahoga DD
   - Other –please fill in

2. What was the main reason you applied for FSP? (SELECT ONE)
   - We needed a specific service that I knew the program offered.
   - We were hoping the program could help us in some way.
   - We were looking for some financial assistance with services.
   - Someone applied for us.
   - Someone told us to apply for the program.

3. Did you use DDS's Family Supports funding in the last 12 months?
   Yes NO

4. (CONTINGENT on #3) IF YES:
What service/resource did you use? (check all that apply)
How useful was this service? (SELECT ONE)
• Special Equipment 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Respite Care 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Recreation/Leisure 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Camp Assistance 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Incontinence Supplies 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Specialized Nutrition 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Therapy (age 0-3) 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful

4. (CONTINGENT on #3) IF NO:
Why didn't you use any services in the last 12 months? (SELECT ONE)
   - COVID-19 pandemic related closures (i.e., camp closure) or concerns (i.e., didn't feel safe)

- We weren’t sure exactly what services were available
- We needed more help to access a covered service or item (like finding a camp or a respite provider).
- The item or service we wanted was paid for in a different way
- We did not want or need services
- Our needs changed and we started working with a case manager.
- Family Supports does not cover the resource/service of interest. Tell us what service you were interested in: ___

5. Would you recommend DDS’s Family Supports Program to other families who may benefit?
    - Yes
    - No
    - Maybe

6. DDS & External Agency Family Supports Program staff respond to questions in a timely manner:
    - Strongly Agree
    - Agree
    - Neutral
    - Disagree
    - Strongly Disagree

7. DDS Family Supports Program information is easy to access through the DDS website (www.dds.org):
    - Strongly Agree
    - Agree
    - Neutral
    - Disagree
    - Strongly Disagree

8. The DDS Family Supports Program online application is easy to understand/ complete:
    - Strongly Agree
    - Agree
    - Neutral
    - Disagree
    - Strongly Disagree

9. Overall, we are satisfied with DDS’s Family Support Program services:
    - Strongly Agree
    - Agree
    - Neutral
    - Disagree
    - Strongly Disagree

10. (Contingent on #4 Services Selected - If chose Respite services, this question appeared)
If you used respite, were the forms you need to use:
Easy to find 1 Very difficult 2 somewhat difficult 3 unsure 4 Somewhat easy 5 Very easy
Easy to understand 1 Very difficult 2 somewhat difficult 3 unsure 4 Somewhat easy 5 Very easy
Easy to complete 1 Very difficult 2 somewhat difficult 3 unsure 4 Somewhat easy 5 Very easy

11. (Contingent on #4 Services Selected - If chose Respite services, this question appeared)
If you used camp, were the forms you need to use:
Easy to find 1 Very difficult 2 somewhat difficult 3 unsure 4 Somewhat easy 5 Very easy
Easy to understand 1 Very difficult 2 somewhat difficult 3 unsure 4 Somewhat easy 5 Very easy
Easy to complete 1 Very difficult 2 somewhat difficult 3 unsure 4 Somewhat easy 5 Very easy

12. Would you recommend other changes to the program? Are there services the program does not provide that you think should be included?

Please answer the following questions for the person enrolled in the program:
13. Race (drop down options: White, Black, Asian, American Indian/Native American, Native Hawaiian/Pacific Islander, 2 or More Races, Other)

14. Ethnicity (drop down: Hispanic, NonHispanic)

15. Gender (drop down: Female, Male)

16. Age (enter number)

17. Does the person enrolled in FSP experience any of the following (select all)?
- Mobility challenges
- Mental health or behavioral challenges
- Communication challenges

APPENDIX D

Family Support Nonparticipant Survey

1. When was the last time you participated in DDS's Family Supports Program? (SELECT ONE)

- Within the last 12 months (since July 2021)
- 1-3 years ago (Sometime between 2019-2021)
- More than 4 years ago (2018 or before)
- Unsure/I don't remember

2. How long did you participate in the DDS's Family Supports Program? (SELECT ONE)

- 1 year or less
- 2-4 years
- 5 years or more
- Unsure/I don't remember

3. When you originally enrolled in the program, how did you hear about DDS's Family Supports Program? (SELECT ONE)

- Friend or another parent
- DDS or Early Intervention staff
- School
- Community or Support Agency (describe)
- DDS website
- Flier, letter or mail from Cuyahoga DD
- Other –please fill in

4. What was the main reason you applied for the FS program? (SELECT ONE)

- We needed a specific service that I knew the program offered.
- We were hoping the program could help us in some way.
- We were looking for some financial assistance with services.
- Someone applied for us.
- Someone told us to apply for the program.

5. When you were in the Family Supports Program, did you use any of your funding?

Yes NO

6. (CONTINGENT on #5) IF YES:
What service/resource did you use? (check all that apply)
How useful was this service? (SELECT ONE)
• Special Equipment 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful

• Respite Care 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Recreation/Leisure 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Camp Assistance 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Incontinence Supplies 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Specialized Nutrition 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful
• Therapy (age 0-3) 1 Very unhelpful 2 somewhat unhelpful 3 unsure 4 Somewhat helpful 5 Very helpful

6. (CONTINGENT on #5) IF NO:
Why didn't you use any services when you were in the Family Supports program? (SELECT ONE)

- COVID-19 pandemic related closures (i.e., camp closure) or concerns (i.e., didn't feel safe)
- We weren't sure exactly what services were available
- We needed more help to access a covered service or item (like finding a camp or a respite provider).
- The item or service we wanted was paid for in a different way
- We did not want or need services
- Our needs changed and we started working with a case manager.
- Family Supports does not cover the resource/service of interest. Tell us what service you were interested in: ___
- Other (please describe):

7. Please tell us why you no longer participate in the Family Supports Program?

- We now work with a case manager and are no longer eligible for the Program
- We are no longer eligible for the program because the person with a disability doesn't live with family anymore
- We got the item or service we needed and don't need anything else right now. We plan to reapply when or if we need services in the future.
- We did not want or need any services from the FS program or DDS.
- The program was too complicated or difficult to use.
- Family Supports does not provide the type of support we need. Please describe what kind of support you need:
- Other (please describe):

8. Based on your experience when you were active in the DDS Family Supports Program,
would you recommend the program to other families who may benefit?

- Yes
- No. If Not, please tell us why:

- Maybe

Please answer the following questions based on your experience when you were active/enrolled in the Family Supports program:

9. DDS & External Agency Family Supports Program staff responded to questions in a timely manner:

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

10. DDS Family Supports Program information was easy to access through the DDS's website (www.dds.org):

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

11. The DDS Family Supports Program application was easy to understand/complete:

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

12. Overall, we were satisfied with DDS's Family Support Program services:

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

13. Would you recommend other changes to the program? Are there services the program does not provide that you think should be included?

Please answer the following questions for the person enrolled in the program:

14. Race (drop down: White, Black, Asian, American Indian/Native American, Native Hawaiian/Pacific Islander, 2 or More Races, Other)

15. Ethnicity (drop down: Hispanic, NonHispanic)

16. Gender (drop down: Female, Male)

17. Age (enter number)

18. Does the person enrolled in FSP experience any of the following (select all)?
    - Mobility challenges
    - Mental health or behavioral challenges
    - Communication challenges

APPENDIX E

Family Support Participant Interview Script and Questions

A. Welcome and Introductions - greet participant, introduce myself and discuss my role

- My role in this interview as a researcher, not as an agency employee although I am employed by the agency.
- I will share themes I find in my research with the agency for improvement of the program.

B. Review confidentiality and invitation to participate document

- No identifying information will be shared with the agency, or in a summary of my research. Participants will be asked to select a pseudonym.
- We are able to stop any time. If there is a question you don't feel comfortable answering a question, you can skip it.
- Obtain verbal consent to record the interview and transcribe it.

C. Background and purpose of the research project

- Some states do not have family support programs at all; in this state program availability varies on where you live in the state
- With reduced numbers of paid caregivers overall there is increased interest in programs that allow people with disabilities to stay in their homes longer.
- Interested in what services are most useful, overall satisfaction with FS program, and how this information might be useful to the field as a whole.

D. Review of the purpose of the FS program for the agency

> The agency intends for the FS program that offers flexible service options within a limited annual budget amount for individuals with DD who live with their families. A large portion of the agency budget is spent on funding services for people who have significant needs who do not have family to support them. However, the agency values the time, effort, and contributions families make to supporting individuals with DD and wants to have a program that allows everyone eligible for board services to access some services, even if the annual budget amount is capped.

E. Any questions before we begin?

Interview Questions

1. Tell me about (name of person with disability). How old is he/she? What do they like to do? Do they attend school or work?
2. How long have you been enrolled in the Family Support program?
3. Tell me about the services you have accessed in the program. (prompting questions if needed: what were the services you used and how often did you use them?)
4. How did you feel about X service? (prompting questions if needed could be - were you satisfied with the service? How was it useful to your family?)
5. In your experience, did the services you used through the FS program offer you any relief or support in providing care to (individual's name)? How did they or did they not provide you support.
6. Describe your experience applying for the program and accessing services. Were these positive or negative experiences for you?
7. Tell me about your interactions with the FS program staff. (prompting questions if needed - Are they helpful? Do you feel the ability to reach out to them if you have questions? Are they kind? Knowledgeable?)
8. Are there other services or things you need but aren't able to get through the FS program? Tell me about how those would be helpful to you.
9. Overall, how supported do you feel in your ability to care for X?
10. Do you have suggestions for how the agency can improve the FS program?
11. Is there anything else you would like to share with me?

APPENDIX F

Family Support Non-Participant (Previously Enrolled) Interview Script and Questions

A. Welcome and Introductions - greet participant, introduce myself and my role
  - My role in this interview as a researcher, not as an agency employee although I am employed by the agency.
  - I will share themes I find in my research with the agency for improvement of the program.

B. Review confidentiality and invitation to participate document
  - No identifying information will be shared with the agency, or in a summary of my research. Participants will be asked to select a pseudonym.
  - We are able to stop any time. If there is a question you don't feel comfortable answering a question, you can skip it.
  - Obtain verbal consent to record the interview and transcribe it.

C. Background and purpose of the research project
  - Some states do not have family support programs at all; in this state program availability varies on where you live in the state
  - With reduced numbers of paid caregivers overall there is increased interest in programs that allow people with disabilities to stay in their homes longer.
  - Interested in what services are most useful, overall satisfaction with FS program, and how this information might be useful to the field as a whole.

D. Review of the purpose of the FS program for the agency
  - The agency intends for the FS program that offers flexible service options within a limited annual budget amount for individuals with DD who live with their families. A large portion of the agency budget is spent on funding services for people who have significant needs who do not have family to support them. However, the agency values the time, effort, and contributions families make to supporting individuals with DD and wants to have a program that allows everyone eligible for board services to access some services, even if the annual budget amount is capped.

E. Any questions before we begin?

Interview Questions

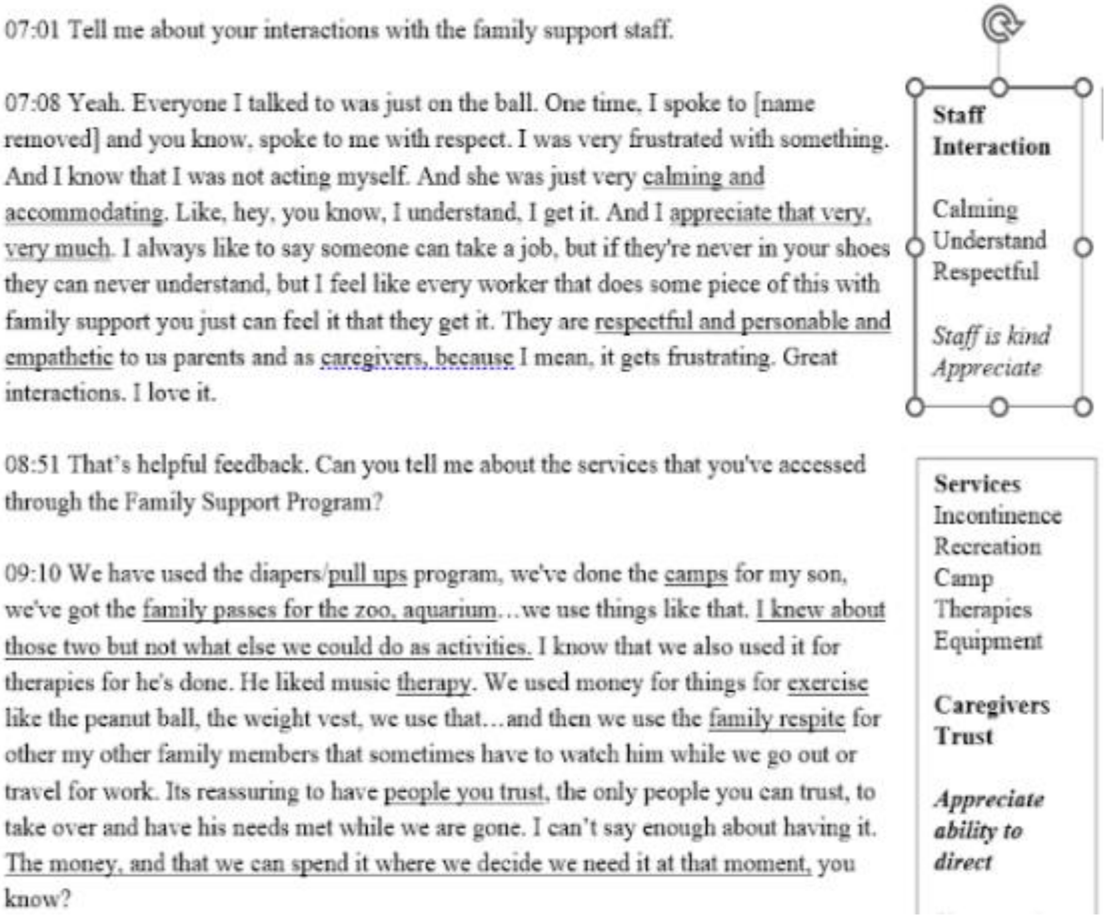
1. Tell me about (name of person with disability). How old is he/she? What do they like to do? Do they attend school or work?

2. Describe your experience in the Family Support program. (prompting questions if needed - how did you find out about the program? How long did you participate?)
3. Tell me about the services you accessed in the program, if you used any services. (prompting questions if needed: what were the services you used and how often did you use them?)
4. How did you feel about X service? (prompting questions if needed could be - were you satisfied with the service? How was it useful to your family? OR, if you didn’t access any services, how did you feel about that experience?)
5. In your experience, did the services you used through the FS program offer you any relief or support in providing care to (individual’s name)? How did they or did they not provide you support.
6. Describe your experience applying for the program and accessing services. Were these positive or negative experiences for you?
7. Tell me about your interactions with the FS program staff. (prompting questions if needed - Were they helpful? Were they knowledgeable? Able to help you? Kind?)
12. Were there services or things you needed but weren’t able to get through the FS program? Tell me what those were and how those would have been helpful to you.
13. Do you still have those same needs?
14. Overall, how supported did you feel in your ability to care for X when you were in the FS program?
15. Do you feel the same or differently now?
16. Do you have suggestions for how the agency can improve the FS program?

17. Is there anything else you would like to share with me?

APPENDIX G

Example of coded interview transcript



07:01 Tell me about your interactions with the family support staff.

07:08 Yeah. Everyone I talked to was just on the ball. One time, I spoke to [name removed] and you know, spoke to me with respect. I was very frustrated with something. And I know that I was not acting myself. And she was just very calming and accommodating. Like, hey, you know, I understand, I get it. And I appreciate that very, very much. I always like to say someone can take a job, but if they're never in your shoes they can never understand, but I feel like every worker that does some piece of this with family support you just can feel it that they get it. They are respectful and personable and empathetic to us parents and as caregivers, because I mean, it gets frustrating. Great interactions. I love it.

Staff Interaction

Calming
Understand
Respectful

Staff is kind
Appreciate

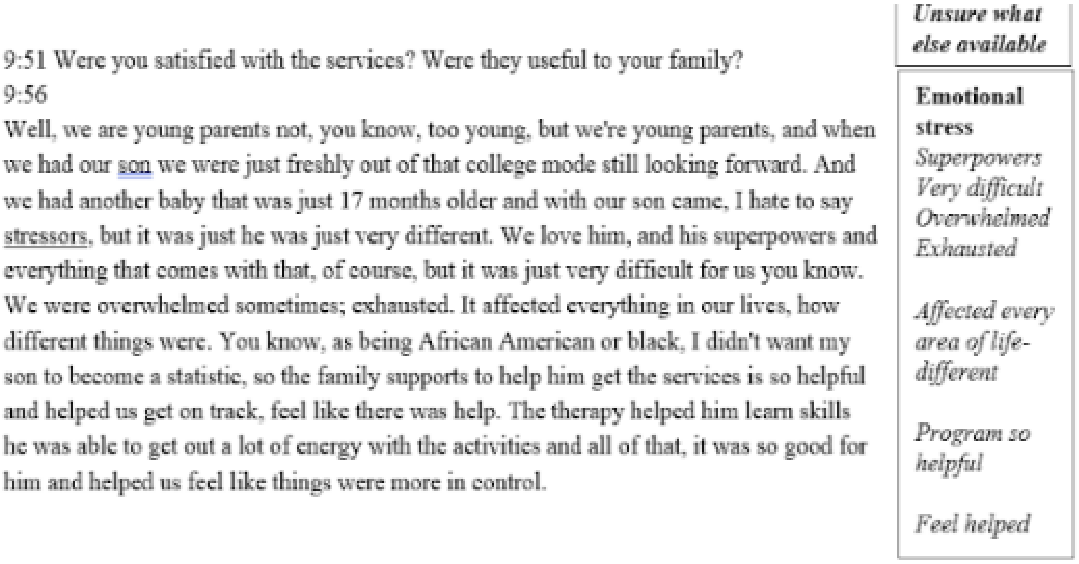
08:51 That's helpful feedback. Can you tell me about the services that you've accessed through the Family Support Program?

09:10 We have used the diapers/pull ups program, we've done the camps for my son, we've got the family passes for the zoo, aquarium…we use things like that. I knew about those two but not what else we could do as activities. I know that we also used it for therapies for he's done. He liked music therapy. We used money for things for exercise like the peanut ball, the weight vest, we use that…and then we use the family respite for other my other family members that sometimes have to watch him while we go out or travel for work. Its reassuring to have people you trust, the only people you can trust, to take over and have his needs met while we are gone. I can't say enough about having it. The money, and that we can spend it where we decide we need it at that moment, you know?

Services
Incontinence
Recreation
Camp
Therapies
Equipment

Caregivers
Trust

Appreciate ability to direct



9:51 Were you satisfied with the services? Were they useful to your family?
9:56
Well, we are young parents not, you know, too young, but we're young parents, and when we had our son we were just freshly out of that college mode still looking forward. And we had another baby that was just 17 months older and with our son came, I hate to say stressors, but it was just he was just very different. We love him, and his superpowers and everything that comes with that, of course, but it was just very difficult for us you know. We were overwhelmed sometimes; exhausted. It affected everything in our lives, how different things were. You know, as being African American or black, I didn't want my son to become a statistic, so the family supports to help him get the services is so helpful and helped us get on track, feel like there was help. The therapy helped him learn skills he was able to get out a lot of energy with the activities and all of that, it was so good for him and helped us feel like things were more in control.

Unsure what else available

Emotional stress
Superpowers
Very difficult
Overwhelmed
Exhausted

Affected every area of life-different

Program so helpful

Feel helped

APPENDIX H

Letter to Participants

Dear [NAME]:

Thank you for being a part of the DDS Family Supports Program!

It is important to us at DDS to support families as they care for their loved ones with developmental disabilities. While we partner with External Agency to help us administer the program, the Family Support program is completely funded by DDS to help individuals access services that might be helpful to them.

Our goal is to provide high-quality supports to people with developmental disabilities, and we are always looking for ways we can improve. We are partnering with a University of Dayton Doctoral student to conduct research on our Family Supports Program, and we need your input! We would like you to complete a short survey about your experience with DDS's Family Supports Program.

Important information about the survey:

- Whether or not you complete the survey DOES NOT affect your participation in the Family Supports Program.

- Your responses will be anonymous, so you can feel comfortable giving us honest and candid feedback about the program.

- At the end of the survey, you will be able to enter a drawing to win one of ten (10) $50 gift cards. Gift card winners will be drawn on June 15 and June 16, 2022. Winners will be notified by email first, and then by phone. If you are completing the survey on paper, **please be sure to mail the survey and entry form back by June 10, 2022.**

We are also looking for volunteers to participate in a follow-up interview, where you will be able to give us even more feedback about the Family Supports program. If you are interested in participating in an interview, please complete the contact card included in this mailing and return it to us by June 10, 2022.

If you prefer to complete your survey and enter the drawing for a gift card electronically, you can do so by going to this address: XXX or scanning this QR code.

Thank you for giving us your valuable feedback about our Family Supports Program. We look forward to hearing what aspects of the program are most helpful to you and what can be improved!

Sincerely,

XXX

CEO, DDS