Focus Group & Survey Report

Strive to Thrive:
Researching Aging Caregiving Families Project

Prepared for the Florida Developmental
Disabilities Council

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Study Report

Prepared for:
Florida Developmental Disabilities Council

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Executive Summary

Overview

Strive to Thrive is a multi-phase research project designed to understand what enables aging families of individuals with intellectual and developmental disabilities (IDD) in Florida to thrive. The mixed methods study utilized focus groups and a statewide survey to examine family experiences, strengths, support needs, and systemic barriers. The findings provide valuable insight into what contributes to family thriving and offer recommendations for improving services and supports.

Methods

Focus Groups

A total of 7 focus groups and 4 interviews were conducted with 38 participants, including 21 family members and 17 adults with IDD. Sessions were held both in person and online.

Online Survey

An online survey was developed using an environmental scan, pilot tested in English and Spanish, and revised based on expert and participant feedback. It included validated scales on thriving, social support, caregiving, and service needs. A total of 198 valid responses were collected from aging family caregivers.

Key Findings

Focus Groups

A thematic analysis yielded five central themes from the focus groups:

- Informal Supports for Thriving.. Key sources of support included extended family, faith communities, friends, and reciprocal relationships with the person with IDD. Caregivers described these networks as vital to their emotional well-being and resilience.
- Personal Strengths/Resources. Both caregivers and people with IDD identified personal traits such as positivity, hobbies, and advocacy as important. Individuals with IDD highlighted self-advocacy and meaningful roles, while caregivers emphasized optimism and persistence.
- Decision-Making Supports. Caregivers and people with IDD described a shift from guardianship to supported decision-making. Promoting autonomy and self-direction was seen as essential to thriving.

- Supports for Independent Living. Participants emphasized the importance of access to transportation, safe housing, and employment opportunities. Many adults with IDD aspired to live independently and contribute meaningfully to their communities.
- Formal Supports/Services. Families described a need for more consistent, accessible, and comprehensive services. Barriers included long waitlists, fragmented systems, and mistrust of disability service systems.

Online Survey

- **Participant Characteristics**. The final sample included 198 aging family caregivers of individuals with IDD across Florida. The majority were female, aged 50 and older, and primarily parents of the individual with IDD. Respondents represented a diverse range of racial, ethnic, socioeconomic, and geographic backgrounds. Most were unpaid caregivers, and many reported providing extensive care hours each week (average of 60 hours).
- **Differences in Caregiver Thriving by Caregiver and Family Member with IDD Characteristics.** Several variables were associated with significantly different thriving scores:
  - Caregivers of adults with IDD reported **higher thriving** than those caring for children (0–21 years).
  - Caregivers whose family members lived outside the home reported **higher thriving** than those whose relatives lived in the same household.
  - Female caregivers and caregivers of other genders reported **lower thriving** than male caregivers.
  - Caregivers supporting individuals with behavioral challenges had **lower thriving** scores.
- **Linear Regression**. Multiple linear regression identified key predictors of caregiver thriving:
  - The strongest positive predictors were:
    - Higher levels of social support
    - Higher levels of social participation
  - Unmet service needs and supporting a family member with aggressive or challenging behaviors were negatively associated with thriving.
- **Open-Ended Responses**. Qualitative responses reinforced the quantitative findings, highlighting the emotional and physical toll of caregiving, especially in the absence of adequate services. Respondents emphasized the need for respite, support with long-term planning, and opportunities to engage with peers and their communities.

Discussion

Seven central insights were drawn from the data analyses:

1. **Social support and social participation were strong predictors of thriving**. Programs that foster caregiver connection and engagement are essential.
2. **Female caregivers and caregivers of other genders reported lower thriving than male caregivers**. Female caregivers may require tailored supports to improve thriving outcomes.
3. **Caregivers whose family members lived outside the home experienced higher thriving**. Families benefit when adults with IDD can live with supports outside of their own home.
4. **Caregivers of adults with IDD had significantly higher thriving than those caring for children/youth.** Caregivers of younger individuals with IDD face different challenges than those caring for adults.
5. **Behavioral challenges in the person with IDD significantly reduced caregiver thriving**. Families supporting individuals with aggression or challenging behaviors need specialized resources and services.
6. **Personal strengths could be a key part of thriving**. Personal resilience, optimism, and community belonging helped caregivers to thrive.
7. **Thriving scores were found to be higher among caregivers who did not have unmet service needs.** Increasing access to core services like respite, transportation, and employment supports is critical.

Recommendations

Eight key recommendations emerged:

1. **Strengthen Social Support and Social Participation Opportunities.** Social support and participation were the strongest predictors of caregiver thriving. Programs that foster peer connection, community engagement, and opportunities for meaningful relationships for both caregivers and individuals with IDD.
2. **Provide Gender-Sensitive Support Strategies.** Female caregivers reported lower thriving than male caregivers. Tailored interventions are needed to address the unique stressors and systemic challenges faced by women, including access to emotional and practical supports.
3. **Develop Long-Term Planning and Residential Transition Supports.** Caregivers of individuals who lived outside the home reported higher levels of thriving. Supports are needed to help families navigate residential transitions, including planning for the future care of their relative as they age.
4. **Target Supports Based on Life Stage of Person with IDD.** Caregivers of adult family members with IDD reported higher thriving than those caring for younger

individuals. Support strategies should be tailored to the specific challenges and needs associated with different developmental stages.

5. **Support Caregivers Managing Challenging Behaviors.** Caregivers of individuals with aggressive or destructive behaviors reported significantly lower thriving. Specialized behavioral support services, training, and crisis response resources are needed to ease the burden on families managing complex behavioral needs.
6. **Leverage and Cultivate Personal Strengths and Resilience.** Focus group participants described personal strengths like optimism and adaptability as important contributors to thriving. Policies and programs should nurture these strengths.
7. **Expand and Ensure Access to Formal Supports.** Many caregivers reported a few unmet needs for essential services. Expanding access to these services would directly reduce caregiver stress and improve overall thriving.
8. **Policy and Program Implications.** The findings have direct implications for the design of state-funded services, workforce development, and interagency coordination. Increased investment in family support and integrated aging and disability services is key to helping families move from surviving to thriving.

Conclusion

The Strive to Thrive project highlights the need to better support Florida's aging caregiving families of individuals with IDD. By centering the voices of caregivers and people with IDD themselves, this study offers a more holistic and strengths-based understanding of what it means to thrive. The findings underscore that thriving is possible, but only when families have access to consistent formal supports, strong social connections, and opportunities for autonomy and planning.

Introduction

> “**Thriving is the state of positive functioning at its fullest range—mentally, physically, and socially**” (Su et al., 2014).

Strive to Thrive is a project that aims to understand, from the perspective of families of people with intellectual and developmental disabilities (IDD) living at home in Florida, what can help advance the person with IDD and the whole family to thrive. Intellectual disabilities (ID) are characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 18 years. Developmental disability is a broader umbrella term that includes intellectual disabilities as well as other disabilities that occur during the developmental stage of life and are typically lifelong. Intellectual and developmental disabilities often co-occur and thus the two terms are commonly combined for research, services, and policies (NICHD, 2023). Thriving is the act of flourishing and is on the opposite end of the continuum from surviving. This project proposes to learn about what helps families move on this continuum beyond surviving to truly having a fulfilling life and thriving in their communities.

Family support plays an important role in people individuals thrive throughout their lives. For those with IDD, this support often begins early in life and continues well into adulthood. Families are central to promoting the dignity and autonomy of individuals with IDD as they grow and evolve. Their involvement spans a wide range of assistance, and the scope of this assistance is usually far beyond that of peers without IDD (Arnold, 2022).

Nationally, about 72% of people with IDD live with family members, yet only 10% of these caregiving families receive formal support from state IDD agencies (Humphrey, 2022). Families tend to provide informal unpaid care for their family members with IDD, and “this overreliance on family members not only leads to poor mental and physical health for caregivers, but also threatens the formal community-based service system, should family members no longer be able to care for their relatives with disabilities” (Friedman, 2023, p.91). Health and psycho-social well-being of family members of people with IDD is negatively impacted because of lifelong caregiving responsibilities (Heller & Schindler, 2009). Additionally, families experience stress because of insufficient and unreliable support services for themselves and their family members with IDD (Griffith & Hastings, 2014).

In Florida, approximately 75% of adults with IDD live with their families. Among them, 31% are cared for by relatives aged 60 or older. The number of adults with IDD residing with aging caregivers is increasing due to longer life expectancies, an aging population, limited availability of formal services, and expanding waitlists. Despite the critical role families play, only 21% of Florida's IDD funding is allocated toward family support (Tanis et al., 2022). Lifelong caregiving responsibilities significantly affect the mental and physical well-being of family members (Heller & Schindler, 2009). In addition, the lack of consistent and adequate support services often contributes to heightened stress among caregivers (Griffith & Hastings, 2014).

As the population of aging caregivers grows, it becomes increasingly important to offer robust support across both the aging and developmental disability service systems. However, these systems can be complex and difficult for families to navigate. Recognizing this, the Florida Developmental Disabilities Council (FDDC) has made supporting aging caregivers a key focus in its current five-year State Plan. The Strive to Thrive project is one aspect of this State Plan to prioritize this population.

An earlier report from the research team described the results of an environmental scan on the topic of thriving across the aging and IDD communities. These environmental scan findings informed the development of both focus group protocols and an online survey in phases two and three of the project. The current report presents the results of these focus groups with people with IDD and aging family caregivers of people with IDD, as well as the online survey completed by family caregivers of adults with IDD.

Definition of Thriving

Su et al. (2014) outline a model of thriving which incorporates seven components:

1) Subjective Well-Being
2) Relationships
3) Engagement
4) Meaning and Purpose
5) Mastery and Accomplishment
6) Autonomy and Control, and
7) Optimism

Each component offers insights into the multifaceted nature of thriving. Applying this model to aging families of individuals with IDD provides a valuable lens to understand both the challenges and strengths they experience. Understanding how these components interact is a way of uncovering the dynamic processes that underpin thriving in this population. This will help us to better identify which elements are most influential in promoting well-being. Based on the model explained by Su and colleagues (2014), thriving could include improvement in quality of life, satisfaction, physical and mental health outcomes, increased social participation, and more.

Thriving in Families of People with IDD

Despite the stress experienced by many families of individuals with IDD, there is evidence of some families successfully adapting, being resilient, and thriving (Blacher & Baker, 2007; Gerstein et al., 2009; Greeff & Nolting, 2013; Herrman et al., 2011; Lafferty at al., 2015). Most thriving research has been conducted on general populations (Su et al., 2014), youth development (Benson & Scales, 2009), and workplace settings (Spreitzer et al., 2005). More recently, scholarship on “critical resilience” and “critical thriving” has expanded the thriving concept to better consider people with marginalized or intersectional identities (Torres et al., 2019).

The “critical resilience” and “critical thriving” approach positions thriving as something which extends beyond survival to challenging oppressive systems (Consoli, 2023). The traditional thriving model typically suggests that individuals with IDD and their families should “overcome” challenges through personal determination, which ignores the reality that many of the obstacles faced by these groups could be due to systemic failures such as lack of accessible transportation or inadequate support services. Using “thriving” as an approach for examining the experiences of aging families of adults with IDD can help us to learn what ensures families move on the continuum beyond surviving to truly having a fulfilling life and thriving in their communities.

Strive to Thrive: A Novel Approach

Research on families impacted by IDD often follows a deficit model, emphasizing the challenges, barriers, and burdens families face. This project shifts away from traditional deficit-based models, instead using a thriving lens which recognizes flourishing despite challenges. By focusing on thriving, we move beyond merely addressing problems and instead spotlight the strengths, resilience, and adaptive capacities within families. This approach encourages creative problem-solving and collaborative strategies that can lead to more sustainable, empowering support systems for aging families of people with IDD.

A thriving perspective also challenges the conventional, linear models of caregiving by incorporating multiple dimensions of well-being. This can include subjective well-being, social connectedness, autonomy, and future planning. This view aligns with contemporary understandings of holistic health and encourages the development of measures that capture the full spectrum of what it means to live well (Keyes, 2022; Su et al., 2014). By adopting this innovative approach, the project opens up new avenues for research, policy, and practice that can transform the support landscape for families facing the unique challenges of IDD caregiving.

Methods

Strive to Thrive is a mixed methods study, incorporating both qualitative (focus groups and interviews) as well we quantitative (survey) data (Plano Clark & Creswell, 2018). Mixed methods studies are designed to get a more robust understanding of a topic. In this study, survey data helps us to look at patterns across many people, but focus groups and interviews allow us to incorporate more in-depth experiences and people's personal stories. Mixed methods is especially helpful when one type of data alone doesn't provide a complete picture, and when researchers want to compare or connect different kinds of findings to make stronger conclusions (Plano Clark & Creswell, 2018).

Focus Groups

To better understand what helps aging family caregivers and individuals with IDD thrive, the research team conducted a series of focus groups and interviews with families in Florida. Interviews were conducted with family caregivers and people with IDD in the event they were unable to participate in focus groups. These sessions aimed to understand the perspectives of families with lived experiences, highlighting both the strengths and challenges they encounter. Separate focus groups were held for people with IDD and for their aging caregivers, including focus groups conducted in Spanish to support linguistic and cultural inclusion. This section describes how these focus groups were developed, piloted, and implemented, as well as key insights gained through qualitative thematic analysis.

Focus Group Development

To develop our focus group protocols and interview guide, we consulted the environmental scan report from phase 1 of the study. This comprehensive environmental scan of both peer-reviewed and grey literature helped us identify key themes related to what enables individuals with IDD and their families to thrive, as well as the barriers they face. The environmental scan also allowed us to review different validated measures for concepts like quality of life and social support, some of which were included in our final survey. Drawing from these findings, we designed a preliminary set of focus group and interview questions that aimed to explore these themes more deeply.

Focus Group Pilots

To ensure clarity and relevance, we piloted the focus group protocol/ interview guide in four separate focus groups conducted over Zoom. A breakdown of these groups is available in Table 1 below.

Table 1. Pilot Focus Group Participants

	Participant Group	# of Participants	Date
1	People with IDD	5	April 2024
2	Aging Family Caregivers	6	April 2024
3	People with IDD, *Spanish-Speaking*	3	October 2024
4	Aging Family Caregivers, *Spanish-Speaking*	3	November 2024
Total number of pilot participants:		**17**	

These pilot sessions allowed us to assess the clarity, relevance, and accessibility of the questions for both audiences: people with IDD, and aging family caregivers. Based on the feedback from the pilot focus groups, we refined the protocols/interview guides to ensure that they were both inclusive and responsive to the lived experiences of participants. Changes to the protocols/interview guides improved the flow and accessibility of the questions before launching the full focus group phase of the study.

We conducted separate focus groups in Spanish to ensure that our research methods were inclusive and culturally responsive to the diverse communities we aimed to engage. These sessions served a dual purpose: first, to test and refine the logistics of using live interpretation in a focus group setting, ensuring smooth communication and participant comfort; and second, to gather feedback from Spanish-speaking participants about the cultural appropriateness of the interview questions and overall process.

Both of the Spanish-speaking pilot focus groups were conducted with a volunteer Spanish-language translator. The researcher would read each question, which would then be interpreted into Spanish. Participants would respond in Spanish and the interpreter would repeat the participants' response in English so the English-speaking researcher could ask follow-up questions. Feedback from these Spanish-speaking focus groups was invaluable in helping us adapt our materials and approach to be more linguistically and culturally relevant. Participants' feedback after pilot focus groups did not include any changes to the focus group scripts.

Family Café Focus Groups

The Family Café is the largest statewide cross-disability event in the United States, held annually in Orlando, Florida. It brings together individuals with disabilities, their families, advocates, and service providers for three days of information, training, and networking.

We selected The Family Café as a recruitment site for our focus groups due to its diverse and engaged audience. During the conference, we conducted three English-language focus groups with individuals with intellectual and developmental disabilities (IDD) and two with aging family caregivers. To acknowledge their time and contributions, participants received $50 Visa gift cards. A breakdown of these groups is available in Table 2 below.

Table 2. Pilot Focus Group Participants

	Participant Group	# of Participants
1	People with IDD	3
2	Aging Family Caregivers	4
3	People with IDD	3
4	Aging Family Caregivers	11
5	People with IDD	7
Total number of Family Café Participants		**28**

Geographical Diversity at Family Café

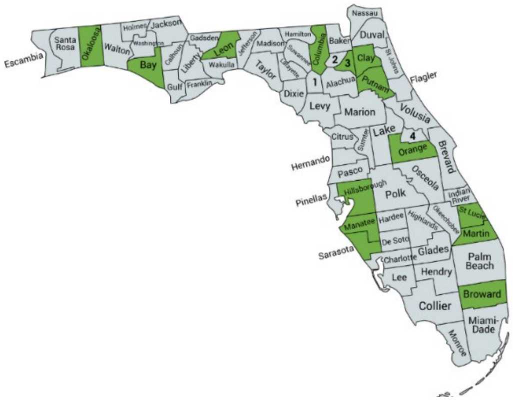


Figure 1. Counties represented in Family Café focus groups

A key advantage of recruiting participants at the Family Café conference was the opportunity to reach a geographically diverse group of individuals from across Florida. The 28 participants who took part in our focus groups represented 14 different counties, offering a broad perspective. Notably, some focus group participants were part of the same family, including dyads and even triads, such as both parents of a person with IDD or a parent and their adult child participating in separate groups. In these cases, multiple individuals from the same county were represented within a single family unit, adding depth to our understanding of family dynamics while still maintaining a wide regional reach.

Miami Focus Groups

In November 2024, two researchers traveled to Miami to conduct in-person focus groups as part of their effort to engage Spanish-speaking communities. These focus groups were planned in close consultation with several members of the FLDDC, who provided input on culturally appropriate locations and helped guide outreach strategies to connect with Spanish-speaking family caregivers and individuals with IDD. We secured conference space at United Healthcare Miami Doral for the sessions and hired a Spanish-language translator to support communication throughout the day.

Despite extensive planning, recruitment proved to be extremely challenging. We reached out to a wide range of community organizations and networks via email and phone, using Institutional Review Board (IRB) approved Spanish-language recruitment materials. Although we received some promising initial responses, we were ultimately unable to recruit enough participants. On the day of the event, only two aging family caregivers arrived, and because they came at different times, we conducted individual interviews rather than a group discussion. Both family caregivers opted to complete their interviews in English, since they were bilingual and felt comfortable without the help of an interpreter.

Unfortunately, no individuals with IDD attended the focus group we had planned in Miami.

Spanish-Speaking Zoom Focus Groups

Due to the low turnout at the in-person Spanish-speaking focus groups in Miami, we pivoted to hosting focus groups via Zoom in an effort to reach additional Spanish-speaking families across the state. After an extended recruitment period, we scheduled one Spanish-language focus group for individuals with IDD and another for family caregivers, both on weekend afternoons to accommodate participants' schedules.

Unfortunately, each of these sessions was attended by only one participant, so the research team conducted individual interviews rather than group discussions. Although a Spanish-language interpreter was hired and present, each participant opted to complete their interview in English. Despite continued outreach efforts, we were unable to recruit additional Spanish-speaking participants for these focus groups.

Focus Group Total and Demographics

Altogether, transcripts from a total of seven focus groups and 4 interviews were included in the final analysis, representing 38 participants. Of these, 21 participants were family caregivers of a person with IDD, and 17 were adults with IDD.

Including the Spanish-language Zoom focus groups ensured that the full range of participant experiences and perspectives is captured. This approach allowed us to make the most of the valuable insights shared across all sessions, especially given the challenges in recruitment and the limited number of participants in the Spanish-language groups.

Table 3. Demographics of Focus Group Participants (N=38)

		Family Members % (n)	**People with IDD** % (n)
Relationship to person with IDD	Parent	86% (18)	-
	Sibling	9.52% (2)	-
	Aunt	4.76% (1)	-
	Self	-	100% (17)
Gender	Female	66.7% (14)	41% (7)
	Male	33.3% (7)	52.9% (9)
	“I use a different term”	-	5.9% (1)
Age	20-30	-	-
	31-40	-	77.8% (7)
	41-50	5% (1)	11.1% (1)
	51-60	40% (8)	11.1% (1)
	61-70	40% (8)	
	71-80	15% (3)	-
Marital Status	Divorced/Separated	19% (4)	-
	Married	61.9% (13)	-
	Widowed	19% (4)	-
Race/Ethnicity	Black/African American	4.8% (1)	13% (2)
	Hispanic/Latino	9.5% (2)	27% (4)
	Two or More Races	4.8% (1)	-
	White	81% (17)	60% (9)
Latino Background	Argentinian	14.3% (1)	-
	Columbian	14.3% (1)	-
	Cuban	66.7% (4)	33.3% (1)
	Puerto Rican	-	66.6% (2)
	Other	14.3% (1)	-
Sexuality	Bisexual	5.3% (1)	16.7% (2)
	“I use a different term”	-	8.3% (1)
	Straight	94.8% (18)	75% (9)
Highest Level of Education	Some high school, no diploma	-	25% (3)
	High school diploma or GED	12.5% (2)	41.7% (5)
	Some college, no degree	25% (4)	25% (3)
	Associate’s (2-year) degree	6.3% (1)	-
	Bachelor’s (4-year) degree	31.3% (5)	8.3% (1)

Table 3 (cont'd). Demographics of Focus Group Participants (N=38)

		Family Members % (n)	**People with IDD** % (n)
Highest Level of Education (Cont'd)	Master's degree	18.8% (3)	-
	Doctoral degree or equivalent	6.3% (1)	-
Employment	Full-time	-	47.4% (9)
	Part-time	46.2% (6)	10.5% (2)
	Retired	-	36.8% (7)
	Unemployed	53.8% (7)	5.3% (1)
Annual Household Income	$0-$30,000	12.5% (2)	-
	$31,000-$60,000	12.5% (2)	-
	$61,000-$90,000	25% (4)	-
	$91,000-$120,000	18.8% (3)	-
	$120,000+	12.5% (2)	-
	I prefer not to answer	18.8% (3)	-

Focus Group Analysis

Researchers used Atlas.ti 25 to support our qualitative thematic data analysis, enabling systematic coding and theme development across interview and focus group transcripts. Thematic data analysis is a method used to identify, analyze, and report themes) within data. It is often employed in qualitative research to help make sense of large amounts of text-based data, such as interview transcripts or survey responses (Braun & Clarke, 2006). Thematic analysis encompasses identifying, analyzing, and reporting repeated patterns in a data set. In addition to describing data, it involves interpretation of the data by selecting codes and constructing themes (Braun & Clarke 2006).

After familiarizing themselves with the data, the research team developed an initial codebook based on the study's guiding questions and refined it through iterative coding and discussion. Our coding process combined both deductive and inductive approaches. We began with a deductive framework, using a codebook informed by the study's guiding questions and existing literature. At the same time, we remained open to new insights, allowing inductive codes to emerge directly from the data during analysis. This flexible and iterative process allowed the research team to capture both expected and novel themes (Gibbs, 2007; Braun & Clarke, 2006). The codebook was refined through multiple rounds of discussion and collaborative coding to ensure consistency and depth of interpretation.

Using Atlas.ti's tools, researchers coded transcripts line-by-line, identified patterns across participant responses, and grouped related codes into broader thematic categories. This process facilitated a structured and transparent approach to identifying key insights across diverse participant experiences.

Focus Group Findings

Findings from focus groups fell into 5 main categories:

- Informal Supports for Thriving
- Personal Strengths/Resources
- Decision Making Supports
- Supports for Independent Living
- Formal Supports/Services

Findings will be discussed in more detail in the Findings section within this report.

Inter-Rater Reliability in Qualitative Coding

One researcher initially coded all eleven focus group and interview transcripts using the Atlas.ti qualitative analysis software. To check the consistency of this coding, a second researcher independently coded one of the transcripts (about 10% of the data) (Halpin, 2024). The two researchers then compared their coding of that transcript side by side using tools from Atlas.ti which helps to visually track agreement and discrepancies. They looked for any differences in how codes were applied and identified segments where their coding did not match. When cross-comparing this transcript, coders agreed on 88.69% of the codes (149 out of 168 codes in total). While there is not a universally accepted percentage for agreement with intercoding, a suggested standard is at least 80% agreement on 95% of codes from a sample of the interview data (O'Connor & Jaffe, 2020), which this study exceeded. The discrepancies were discussed thoroughly until consensus was reached on all codes for total agreement in the end.

The codebook was updated from the discussion with the intercoder. Any such differences were discussed openly, and the researchers worked together to resolve the discrepancies by clarifying the code meanings and agreeing on how each section should be coded. They continued this dialogue until they reached full agreement on the coding for that transcript.

This collaborative process assesses inter-rater reliability, which means checking that another person would interpret and code the data in a similar way. Double-coding a portion of the transcripts and resolving any disagreements is a common practice in qualitative research to ensure the analysis is consistent and dependable. By involving a second coder and reconciling differences through discussion, the team reduces the chance that the findings are biased by one individual's perspective (Gibbs, 2007). In other words, this step helps confirm that the themes and insights identified are not just one person's view but are shared and agreed upon by multiple researchers. These measures strengthen the credibility of the analysis and give confidence that the results are reliable and trustworthy (Gibbs, 2007).

Member Checking with Focus Group Participants

Member checking is important because it helps ensure the findings accurately reflect what participants said and meant, making the results more trustworthy. The research team used member checking to make sure the focus group findings are accurate. Two participants from each group (two people with IDD and two aging family caregivers) were invited to review a written summary of their group's discussion and give feedback on it. This process gave those participants a chance to confirm that the summary captured their thoughts correctly and to point out anything that might have been missed or misunderstood. Neither participant suggested any changes to the research protocol or the analysis.

Online Survey

The online survey was developed through a careful, multi-step process to ensure it reflected the real-life experiences and priorities of people with IDD and their aging family caregivers. Drawing on findings from the project's initial environmental scan and using other scales, such as the Brief Inventory of Thriving (Su et al, 2014), Social Supports Scale (Peeters et al, 1995), and Combo Scale of Caregiving (Heller et al., 1999). The research team incorporated questions that addressed both challenges and supports to thriving experienced by families. The survey went through subject matter experts' review, pilot testing in English and Spanish, formal translation, and multiple rounds of revisions to improve clarity, cultural appropriateness, and accessibility. This section outlines how the survey was designed, tested, translated, revised, and ultimately launched.

Survey Development

Survey questions were developed based on the instruments/measures search and thematic findings of the environmental scan from phase one of the Strive to Thrive project. Researchers took into account the key themes identified in established resources and grey literature regarding thriving in the two target populations: people with IDD, and aging family caregivers of people with IDD. Questions incorporated the identified support needs/barriers and challenges for families, as well as the identified resources and support which helped families thrive. Based on the environmental scan, four existing standardized measures were included in the original survey. After a few revisions based on piloting data as well as recommendations from the Florida DD Council, we retained only three of these scales:

- Brief Inventory of Thriving (Su et al., 2014)
- Social Supports Scale (Peeters et al, 1995)
- Combo Scale of Caregiving (Heller et al., 1999), Caregiver Self-Efficacy and Caregiver Satisfaction subscales (we removed the caregiver burden subscale)

After an initial survey was developed, we requested feedback on the survey from subject matter experts within the Institute on Disability and Human Development (IDHD) at UIC, as well as from the FLDDC. We also requested feedback from two experts in survey design from the IDHD. The initial survey was approved by the UIC IRB in March 2024.

Survey Pilot

Based on a final expected sample size of 300 participants, we conducted pilot testing with 30 individuals (10% of the sample) in order to achieve intra-rater reliability. The piloting began in May 2025. For the initial 10 pilot participants, researchers conducted the survey live over Zoom so participants could give instant feedback, then repeated this process over Zoom within two weeks of the initial pilot testing date. The remaining 20 pilot participants completed the survey online on their own, with additional feedback through open-ended questions.

The team made revisions to the survey based on participant feedback. This included many minor changes such as:

- Adding examples to responses which were unclear to families
    - Example: a response option on a multiple-choice question namely “sensory disability” was revised to “sensory disability (e.g. blind or deaf)”
- Adding certain response options to questions on thriving recommended by families during pilot testing of the survey
    - Example: “transportation” was added to the list of items which might help a family thrive
- Revising the layout of certain questions
    - Example: we originally asked what helps the RESPONDENT thrive within the same question we were asking about what helps the FAMILY MEMBER WIITH IDD to thrive. This proved confusing to participants, so we decided to ask this in two separate questions.

Another major revision made after piloting was removing some of the validated scales and replacing some other validated scales with shorter versions. Pilot participants felt the survey was too long. In response, our team replaced the Comprehensive Inventory of Thriving (54 items) with the Brief Inventory of Thriving (10 items). Two scales were removed entirely, the General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) and the Family Quality of Life Scale (Hoffman et al., 2006).

Spanish Translation

The survey was formally translated into Spanish by Lingua Translations, a professional translation service, and certified for accuracy and completeness. Following this official translation, minor wording changes that occurred during the finalization of the survey were reviewed and translated by a fluent Spanish-speaking staff member at the IDHD at the University of Illinois Chicago (UIC) to ensure consistency and clarity.

Spanish Survey Pilot for Cultural Appropriateness

To evaluate the cross-cultural adaptation of the final translated survey, 3 Spanish-speaking pilot participants completed the survey in November 2024 and gave feedback specifically on its cultural appropriateness. One question was revised based on this feedback. The question originally read “El miembro de su familia con DID, ¿tiene un tutor?” (Translation: Does your family member with IDD have a guardian?). There was some confusion about whether this question was regarding legal guardianship or a school tutor. The question was revised to read “El miembro de su familia con DID, ¿tiene un tutor legal?” (Translation: “Does your family member with DID have a legal guardian?”).

Since significant changes were made later to the survey in January 2025, we recruited 2 additional Spanish-speaking pilot participants to give feedback on cultural appropriateness. This was conducted in April 2025. Since the pilot participants did not suggest any changes to this version of the survey reporting that the survey was culturally appropriate, the survey remained unchanged.

Online Survey Launch

The survey was initially launched in February 2025 and received 50 responses before the FLDDC requested revisions. These revisions primarily focused on the removal of the Depression, Anxiety, and Stress Scale (Henry & Crawford, 2005), as well as the inclusion of new items which may indicate thriving based on the feedback of Florida DD Council staff members (e.g. “I am involved with other I/DD families locally or statewide”).

In response to this feedback, the research team updated the survey and re-submitted it to the DD council. Once approval was attained, the research team submitted the revised survey to the IRB at UIC and received approval for the revised version in April 2025.

The updated survey was re-launched following the FLDCC Advisory Taskforce meeting on April 10, 2025. Data from the original 50 respondents was retained in the final analysis. While some items were removed in the revised survey, the responses from these first 50 participants remain valuable for the overall dataset. For the newly added questions, responses from the first 50 participants were marked as missing, but their data contributed meaningfully to the analysis with regards to the existing questions. This approach ensured the retention of useful data while allowing for the integration of new items into the survey.

Online Survey Recruitment

Survey recruitment began in January 2025. Researchers e-mailed and called many provider organizations, advocacy organizations, families, and community leaders across Florida with a flyer and link for the survey. Some of these contacts were provided by members of the Florida DD Council Aging Taskforce, including representatives from the Florida Partners in Policymaking, and the University of Central Florida’s Center for Autism and Related Disabilities (CARD). As stated earlier, active survey recruitment was paused between February 2025-April 2025 while the team awaited IRB approval for the survey changes based on Florida DD Council feedback.

Active recruitment for the survey resumed in April 2025. In addition to partner organizations and representatives recommended by the Florida DD Council Aging Taskforce, research team members individually reached out to service providers, organizations, social groups, day programs, and other stakeholders in Florida to recruit independently. Some of the organizations and individuals contacted by the research team included: All Florida Arc branches, all Florida SAND branches, both Florida UCEDDs, All Florida FCC chairs, and all easily accessible FCC, SAND, and Arc contacts or staff (Depending on each website and the contact information shared on those websites). Additional personal connections from the research team were also utilized in recruitment including family members, day programs with personal ties, previous employers based in Florida, previous colleges based in Florida, and social groups with personal ties. The researchers utilized the State of Florida Agency for Persons with Disabilities Resource Directory to identify organizations and individuals who were likely to meet the criteria for survey inclusion. A key research team member spent much of May 2025 calling 100+ organizations, and e-mailed 200+ organizational representatives in April 2025 based on this directory.

To maximize outreach, the research team also relied on snowball recruitment by encouraging participants and partner organizations to share the survey within their personal and professional networks. This approach helped extend outreach to a broader and more diverse group of respondents, particularly those who would not have likely been reached through formal distribution channels.

Online Survey Response

The online survey received a total of 334 responses (320 in English, 14 in Spanish). Of these, 6 did not consent. An additional 19 were disqualified from completing the survey because they did not meet inclusion criteria (6 were not family caregivers, 13 were under age 50). A total of 44 did not provide any answers past consent, and 67 did not complete enough of the survey for their responses to be included in the analysis. This left a total of **198** survey respondents to be included in the final analysis (193 English and 5 Spanish).

Survey Data Analysis

The Statistical Package for the Social Sciences (SPSS), version 30.0.0.0 (172) was used to analyze the quantitative data. Descriptive statistics were used to present the demographic characteristics of the caregiver and family members with IDD characteristics. Means, ranges, and standard deviations were presented for the continuous variables, and frequencies and percentages were presented for the categorical variables. Independent samples t-tests and one-way between subjects ANOVA tests were conducted to examine the differences in outcome variable (i.e., Brief Inventory Thriving Score) based on the caregiver and family members with IDD characteristics. Simple univariate and multiple linear regression were calculated to examine associations between the outcome variable and the predictor variables. Assumptions for the linear regression model were tested by looking at the correlations between the predictor variables, multicollinearity diagnostics for variance inflation factor (VIF) and tolerances, case wise diagnostics for standardized residuals, and Cook's distance for checking the magnitude of influence a predictor variable has on the predicted value of the outcome variable. Because using a traditional p value level of 0.05 could fail to identify variables of known importance (Bendel & Afifi 1977; Mickey & Greenland 1989), for the multiple linear regression model, only those other predictor variables were included that showed a p value of 0.20 or less in the univariate simple linear regressions. Bootstrapping method was used to determine the robustness of the model by selecting 1000 number of random subsets from original dataset (Banjanovic & Osborne, 2016). A standard level of significance associated with probability levels of P <0.05 was used.

Measures

Independent Measures

Caregivers' Characteristics

Caregiver age (was divided into two groups: 50-64 years and 65 years or more), race (divided into two groups: white and non-white) gender (divided into three groups: male, female, and other, which included "transexual," "nonbinary," or "I prefer a different term"), marital status (Married, widowed, divorced/separated, prefer not to answer), education (high school graduate or less, some college or associate degree, Bachelor's degree, and Master's or higher), current employment status (yes or no), total number of family members in his/her household including him/her and the care recipient (grouped into 1 to 3, 4 or more) and family annual household income (grouped into $0-30,000, $21,000-60,000, $61,000-90,000, $91,000 and above, prefer not to answer), Paid for caregiving (yes or no), and compound caregiving (caring for more than one individual, yes or no).

Care Recipients' Characteristics

Care recipients' age (was divided into 0-21 years, 22-44 years, and 45 years and above), gender (divided into three groups: male, female, and other , which included "transexual," "nonbinary," or "I prefer a different term"), level of ID (mild, moderate, severe, profound, or unknown), IDD and related conditions (IDD only, IDD + physical disability, IDD + Mental illness, IDD + Sensory Disability), and living arrangement (in the family household, living on their own, supportive living/group home, private/public institutional setting, or other, which included "with family or friends or guardians other than myself," "in a foster or host home," or "other (please specify)"), daily activities (stays home during the day or has activities—employment, school, day program, volunteering—during the day), and has aggressive/destructive behaviors (yes or no).

Other Independent Measures

Caregiver Satisfaction Score

The Combo Scale of Caregiving (Heller et al., 1999) includes three subscales for caregiver self-efficacy, caregiver satisfaction, and caregiver burden. Our survey used only the caregiver self-efficacy and caregiver satisfactions subscales, removing items related to caregiver burden. The caregiver satisfaction subscale demonstrates a high internal consistency (Cronbach's alpha=.93) (Heller et al., 1999).

The caregiver satisfaction scale, part of Heller et al. (1999)'s Combo Scale of Caregiving, has 5 items and is rated on a 4-point Likert scale, 1) Strongly Disagree, 2) Disagree, 3) Agree, and 4) Strongly Agree.

The Caregiver Satisfaction items are:

1. My relative's pleasure over some little thing gives me pleasure
2. My relative shows real appreciation for what I do for him/her
3. Taking responsibility for my relative gives my self-esteem a boost
4. Helping my relative helps me feel close to her/him
5. I really enjoy being with my relative

This independent measure is a sum of these 5 items The score ranges from 5 to 20, with a mean of 15.45 (SD=2.9).

Caregiver Self-Efficacy Score

The caregiver self-efficacy scale, part of Heller et al. (1999)'s Combo Scale of Caregiving, has 5 items and is rated on a 4-point Likert scale, 1) Strongly Disagree, 2) Disagree, 3) Agree, and 4) Strongly Agree. The caregiver self-efficacy subscale's alpha reliability is 0.77 (Heller et al., 1999).

The Caregiver Self-Efficacy items are:

1. I would make a fine model for a parent of a child with a disability
2. I feel I can manage my relative's behavior
3. I meet my own expectations in caring for my relative
4. If anyone can find the answer to what is troubling my relative, I can
5. I honestly believe I have the skills necessary to be a good caregiver to my relative
6. I feel that what I do can help improve my relative's situation

This independent measure is a sum of these 6 items. The score ranges from 5 to 24, with a mean of 17.00 (SD=3.01).

Social Support Score

The Social Supports Scale (SSS), developed by Peeters et al., 1995, is an instrument designed to measure perceived social support.

The SSS Consists of 4 items rated on a 5-point Likert scale, 1) Strongly Disagree, 2) Disagree 3) Neither Agree nor Disagree, 4) Agree, and 5) Strongly Agree.

The SSS items are:

1. There are people in my life who pay attention to my feelings and problems *(Emotional Support)*
2. There are people in my life who appreciate what I do *(Appraisal Support)*
3. There are people in my life who I can get help from if I need it *(Instrumental Support)*
4. There are people in my life who I can talk to about how to handle things *(Informational Support)*

The *instrumental* and *informational* support items was interpreted as "Instrumental Support", while the *emotional* and *appraisal* support items was interpreted as "Intimate Support." The internal consistency for instrumental support and intimate support was high ($\text{Alpha}_{\textit{Instrumental}}$ = 0.80; $\text{Alpha}_{\textit{Intimate}}$ = 0.77) (Peeters et al., 1995).

This independent measure is a sum of these 4 items. The score ranges from 0 to 16, with a mean of 10.64 (SD=2.90).

Social Participation Score

The social participation score was determined based on five questions proposed by the FLDDC. These were rated on a 5-point Likert scale, 1) Strongly Disagree, 2) Disagree 3) Neither Agree nor Disagree, 4) Agree, and 5) Strongly Agree. The Social Participation Score showed high internal consistency (Cronbach's alpha=.78).

The Social Participation Score items are:

1. I find time for outside interests or hobbies of my own
2. I am involved with other I/DD families locally or statewide
3. I connect with friends and family via social media
4. I make it a point to regularly attend religious, social, cultural or recreational events on my own
5. I can meet my own needs for healthcare and relaxation

This independent measure is a sum of these 5 items. The score ranges from 6 to 30, with a mean of 12.00 (SD=3.86).

Number of Reciprocal Supports Received from Family Member with IDD

Previous research has revealed that family caregiving relationships for families of people with IDD are often reciprocal, with mutual (two-way) support rather than only one-way caregiving (Kramer et al., 2013; Heller & Factor, 2008). Because of this, our survey addressed a few key ways participants may be receiving reciprocal support from their family member with IDD.

Participants were asked "In which of the following ways does your family member with IDD help you?" and given the following options:

1. Helps me feel better when upset
2. Helps me with my personal care
3. Helps with household chores
4. Helps financially
5. Keeps me from feeling lonely
6. Shares enjoyable time and activities with me
7. Shares new useful advice and information

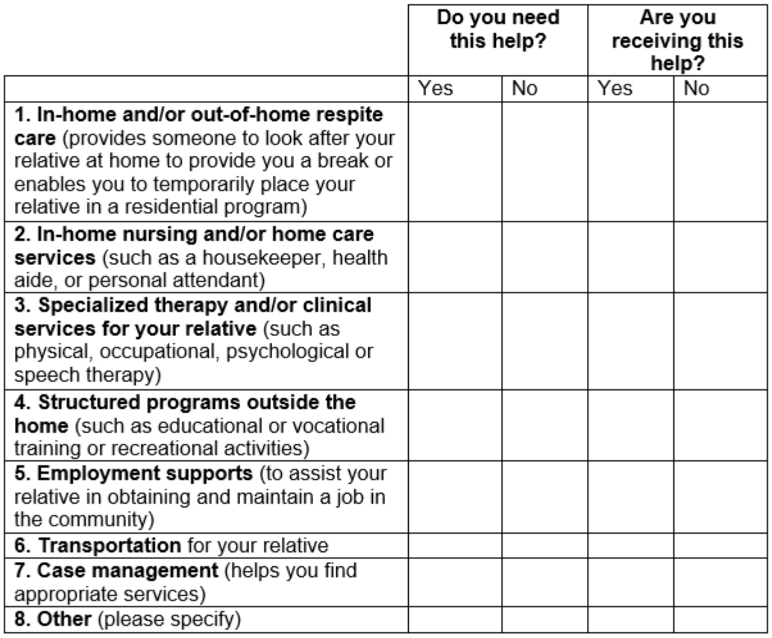
For each item the survey respondent checked, that was calculated as one support received, with a minimum of zero and a maximum of 7.

This independent measure is a sum of these 7 items. The score ranges from 0 to 7, with a mean of 1.89 (SD=1.39).

Number of Formal Services Received

Participants were asked about the formal services they were receiving. For each item, participants were asked whether they need the formal service, as well as whether they are receiving that formal service. There were 8 categories of formal services, including an “other” category.

Each time a participant Marked “yes” to the question “are you receiving this help?” this was calculated as a formal service received. Participants were asked “Are you receiving the following types of services or support for your family member? For each service listed below, indicate whether you need this kind of help AND if so whether you are receiving this help (including private pay)” and given the options in Figure 2 (right).



	Do you need this help?		Are you receiving this help?	
	Yes	No	Yes	No
1. **In-home and/or out-of-home respite care** (provides someone to look after your relative at home to provide you a break or enables you to temporarily place your relative in a residential program)				
2. **In-home nursing and/or home care services** (such as a housekeeper, health aide, or personal attendant)				
3. **Specialized therapy and/or clinical services for your relative** (such as physical, occupational, psychological or speech therapy)				
4. **Structured programs outside the home** (such as educational or vocational training or recreational activities)				
5. **Employment supports** (to assist your relative in obtaining and maintain a job in the community)				
6. **Transportation** for your relative				
7. **Case management** (helps you find appropriate services)				
8. **Other** (please specify)				

Figure 2. Formal Services Questions

This independent measure is a sum of these 8 items. The score ranges from 0 to 8, with a mean of 2.31 (SD=1.83).

Number of Unmet Formal Service Needs

Within the same question as number of formal services received (above, p. 21), participants were asked about their need for each type of formal service needs. When a participant answered “yes” to their need for a formal service, but “no” to whether they are receiving that formal service, this was calculated as an “unmet service need.”

The Unmet formal service needs items are:

1. **In-home and/or out-of-home respite care** (provides someone to look after your relative at home to provide you a break or enables you to temporarily place your relative in a residential program)
2. **In-home nursing and/or home care services** (such as a housekeeper, health aide, or personal attendant)
3. **Specialized therapy and/or clinical services for your relative** (such as physical, occupational, psychological or speech therapy)

4. **Structured programs outside the home** (such as educational or vocational training or recreational activities)
5. **Employment supports** (to assist your relative in obtaining and maintain a job in the community)
6. **Transportation for your relative**
7. **Case management** (helps you find appropriate services)

This independent measure is a sum of these 7 items. The score ranges from 0 to 7, with a mean of 2.01 (SD=2.01).

Time Spent Providing Help to Family Member with IDD

To assess the amount of time participants spent providing help to their family member with IDD, they were asked "In a typical week about how much time do you spend providing help to the individual with IDD (such as dressing, shopping, giving advice, coordinating services, etc.)" They were given an open-ended text box to provide this information. Some participants answered "24/7," which was converted to 168 hours per week.

The score of this independent measure ranges from 0-168, with a mean of 59.67 (SD=55.99).

Outcome Measure

Brief Inventory of Thriving

The Brief Inventory of Thriving (BIT) is a condensed version of the Comprehensive Inventory of Thriving (CIT), and measures psychological well-being across a broad range of dimensions (Su et al., 2014). The BIT has been validated and demonstrates strong psychometric properties. It has shown great internal consistency with alpha coefficients above 0.90 across four cross-validation samples (Su et al., 2014), supporting its use as an accurate and efficient measure of psychological well-being.

The BIT Consists of 10 items rated on a 5-point Likert scale, 1) Strongly Disagree, 2) Disagree 3) Neither Agree nor Disagree, 4) Agree, and 5) Strongly Agree.

The BIT items are:

1. There are people who appreciate me as a person
2. I feel a sense of belonging in my community
3. In most activities I do, I feel energized
4. I am achieving most of my goals
5. I can succeed if I put my mind to it
6. What I do in life is valuable and worthwhile

7. My life has a clear sense of purpose
8. I am optimistic about my future
9. My life is going well
10. I feel good most of the time

The outcome measure is a sum of these 10 thriving items. The score ranges from 10 to 50, with a mean of 36.08 (SD=8.3).

Findings

Focus Group Findings

Separate focus groups and interviews were conducted with aging caregivers of people with IDD and people with IDD. A total of 3 focus groups and 3 one-on-one interviews were conducted with family caregivers. A total of 4 focus groups and 1 one-on-one interview were conducted with people with IDD. Focus groups were open-ended and primarily focused on three main questions:

1) What helps people with IDD who are living with their aging families in Florida to thrive?
2) What helps aging families in Florida to support the person with IDD to thrive?
3) What supports aging families of people with IDD in Florida so they can thrive?

Focus groups and interviews were audio recorded and transcribed verbatim. Qualitative thematic analysis of the transcripts was conducted, where a researcher did a preliminary review of the transcripts, identified preliminary categories and themes, created a codebook, and then coded each transcript using those codes. This codebook was further refined during the coding process, with new codes introduced and some combined, as prominent themes emerged.

Findings from these themes fell under four main categories:

1. Informal Supports for Thriving
2. Personal Strengths/Resources
3. Decision Making Supports
4. Supports for Independent Living
5. Formal Supports/Services

As supported by our earlier literature review, focus groups revealed that the experience of thriving was multifaceted for family caregivers as well as people with IDD. While there was no “one size fits all” set of supports which help families thrive, some common themes emerged about the types of informal and formal support which families found were the most conducive to thriving.

Theme 1: Informal Supports for Thriving

Families and individuals with IDD described many “informal” supports for thriving. These included Support Networks/Friendships; Emotional Support; Instrumental Supports; Reciprocal Support; and Faith & Spirituality. Not all of these informal supports were weighted equally across participants. As a general trend, the most frequently cited informal source of thriving were support networks/friendships, which included extended family.

Support Networks/Friendships

Social support networks was one of the most frequently-cited components for thriving among both family members and people with IDD. These support networks sometimes involved extended family, faith communities, schools, or community day programs. One participant with IDD shared how their entire family network provided emotional support and opportunities for engagement through activities like the Special Olympics torch run. Another participant with IDD similarly remarked “my community helps me thrive… my church family helps me thrive… even my work family helps me thrive,” (M.H.G., Participant with IDD) showing how both personal and professional relationships fuel a sense of purpose in people’s lives.

> “When she's accepted in an area when she feels comfortable and confident … whether it's, you know, church, or if we go to meetings or in Special Olympics … but just in the relationships. **When she's accepted, I can relax**.”
>
> —C.A., Family Caregiver Participant

Multiple family caregivers reported how when their family member with IDD has their own friends and support networks, it helps the entire family to thrive. One mother said, “I mean, we walk up somewhere, and they'll go “Where's [daughter’s name]?... it's very rewarding when you know they do have a little circle of friends.” (V.G., Family Caregiver Participant) Another family member joked about her daughter’s upcoming 30th birthday party, and how the guest list kept expanding. The joy she felt in being able to celebrate with her daughter, her daughter’s extended family, and her daughter’s friends from her day program was palpable.

Family support networks were another key piece of thriving for many families. One participant with IDD said simply “I got a whole bunch of mother and cousins…. they always helped me a lot” (K.S., Participant with IDD). One father explained how his family support network was crucial in both of their thriving, saying “being Hispanics, there's something that comes with the culture where you help support each other, your family is the most important thing, and so it's almost something that you just have to do. And but it turns out that it's something that it also makes you feel good doing” (F.D.M, Family Caregiver Participant). Others found similar support from “chosen family,” as demonstrated by two participants who arrived at a focus group together

> “My community helps me thrive.”
>
> —M.H.G., Participant with IDD

whose daughters were part of the same special needs cheer squad. They were not related, but described their relationship as "'ride or die,' you know? That's like my child-- my child is like hers like and [hers is like mine]" (C.A., Family Caregiver Participant).

A few caregivers specifically touched on the importance of building their own community support networks when they aren't readily available. One caregiver remarked "I want to add one more thing that helps our children thrive, and that's the lay community that you live in. Do the sporting events. When my son-- we signed him up for everything, just sign him up…." (L.H., Family Caregiver Participant). This caregiver went on to describe how important it was to be actively involved in community sports, park district, and other programs in order to build strong friendships and support networks. The same caregiver later described building a support network for her son through church, private school, and other connections, saying "the team that I assembled… is what enabled him to thrive and us to survive" (L.H., Family Caregiver Participant). Another caregiver remarked that community participation is important for his son, and that he didn't want to "create a bubble for him," saying instead that he wants to "let him participate, you know, in the community, and the things will come on time" (E.M., Family Caregiver Participant).

Several caregivers lamented the lack of social or familial support networks in their own lives, particularly for help with instrumental support or future planning. One said "I have someone who has to have one on one supervision all the time for the rest of her life…. and there's not other people who can step in" (N.W., Family Caregiver Participant). Another participant with IDD worried about her own guardianship transferring from her mother to her sister, since her mother lived far away and was in poor health. She said "It's hard because as my mom gets up there, I'm starting to notice that her health is starting to take a toll… I feel scared. I'm confused. I don't know. [Voice choking up with tears]" (B.J., Participant with IDD)

Overall, the voices of these participants demonstrate that thriving is not an individual journey; it is built on relationships. Whether through faith communities, family bonds, or friends, these connections provide emotional scaffolding, practical support, and a sense of purpose. When building systems that support aging families of people with IDD, it is essential to recognize, sustain, and honor the existing networks that make thriving possible and build on them for families who are struggling to find supportive communities.

Emotional Support

People with IDD often relied on their family caregivers, particularly their parents and sometimes others in their family, for emotional support. This emotional support was seen as a key component of thriving. One explained this emotional support from her mother, saying “[my mom tells me] wherever that negative energy, you can let out at the moment and give me a hug … it's going to help you fighting out your day” (G.C., Participant with IDD). Another participant who had IDD and autism, explained “I have meltdowns and stuff, my aunt, my cousin, like, talk to me and stuff, and it, like, calms me down and stuff when they have like conversations with me… it helps me, like, get back to like, into my groove and stuff so I can, like, act my age again, and instead of, like, acting like a kid” (T.S., Participant with IDD).

Family caregivers were less likely to discuss their need for emotional support, despite many reporting high levels of stress and anxiety.. When they did mention instrumental support, they were less likely to receive this support from their family member with IDD than from another source, like a spouse, friends, or a faith community. Family caregivers were, however, more likely than people with IDD to mention their need for instrumental support as a component of thriving.

Instrumental Support

Instrumental support refers to practical, hands-on help that people receive to meet daily needs. This can include help with transportation, self-care, managing finances, preparing meals, or attending appointments. This type of support is often provided by family members, paid caregivers, or support workers, and they are essential for individuals with disabilities to live independently and safely in their communities. Some family caregivers discussed their need for more help in providing instrumental support for their family member with IDD, feeling exhausted and overwhelmed with the 24/7 nature of their role. One said “it gets to be where you feel exhausted… it's not going to get any better. And it's just, you know, it's just sits here and I’m never gonna get out from under this burden” (B.F., Family Caregiver Participant). While family caregivers found joy and love in their caregiving role, it was clear that many also needed stronger support networks, as they often felt like they were the sole lifeline for their child.

When one participant with IDD asked about what a guardian should be doing for her, she explained “what about all the necessities, like cooking, cleaning, helping us make our beds, all of that, including trash? I mean, come on” (B.J., Participant with IDD). When the researcher followed up with her, asking if those are things a guardian should be doing, she responded “No, but at least assisting” (B.J., Participant with IDD). Another expressed pride in not needing significant instrumental support, saying “I do everything by myself. I know how to cook, I know how to wash clothes…” when the researcher followed up, asking if the participant likes making their down decisions, the participant responded “yeah” (D.M., Participant with IDD). There was a sense of satisfaction for her to be able to experience independence and autonomy in these tasks. Similarly, another 35-year-old participant with IDD explained his goal of living independently and taking care of more of his own instrumental support, explaining he was “just trying to make my parents proud, you know?" (M.H.G, Participant with IDD). This desire to make his parents proud reflects not only his personal independent living goal, but also the emotional connection and sense of responsibility many people with IDD feel toward their families. These examples of striving for autonomy illustrate that support is not one-directional; in the next section, we explore how people with IDD also provide meaningful support to their family caregivers.

Reciprocal Support

A key to understanding the participants' family dynamics is that both support and thriving were rarely described as a one-way street. Families described thriving as an entire family unit, not just as individual members. They also described both the support people with IDD *receive* from their family caregivers as well as the support people with IDD *give* to their family caregivers in a complex reciprocal relationship.

This contrasts with traditional models of caregiving, which often conceptualize the relationship as unidirectional, where caregivers provide support without acknowledging the potential for care recipients to offer support in return. Such models tend to overlook the dynamic, relational nature of caregiving, which can involve mutual influence and shared growth. This aligns with existing research which highlights the way informal care dynamics are fundamentally relational and often reciprocal, with caregiving roles being complex and overlapping (Lyons et al., 2002).

Both participants with IDD and family caregiver participants remarked on the care they provide to one another, including emotional, instrumental, and other types of support. One participant with IDD stated simply "I love my mom. She needs that love" (K.S., Participant with IDD). Another described using his SSI check to take his mother out do dinner, following up by saying "My mom has health issues. I want to try help her out much I can. But even my dad has health issues… so I take care of both of them" (J.G., Participant with IDD).

> "I love my mom. She needs that love."
>
> —K.S., Participant with IDD

Families in these focus groups emphasized a more holistic view, recognizing that both giving and receiving support contribute to the well-being and thriving of the entire family unit.

Faith & Spirituality

A subset of participants referenced faith, religious communities and services, and spirituality as components of thriving in their lives. For many, the community support and inclusion found in church seemed to be the primary driver for thriving. One family caregiver said “getting him plugged into our church and worship music” helped her son to thrive in a time when he was having behavior challenges related to a secondary diagnosis of intermittent explosive disorder (L.M., Family Caregiver Participant). The same family caregiver later said, “our church family, absolutely accepted him…” and described how they prepared a special graduation mass for him when he graduated, despite the limitations of Covid and the hesitation of the parish’s priest (L.M., Family Caregiver Participant). Another Spanish-speaking caregiver emphasized the importance of their child attending church social activities, including the celebration of San Martín Day. One participant was the pastor of a church, and described how his daughter’s church homeschool community was part of her ability to thrive when they felt the school district wasn’t providing adequate supports. Several participants with IDD also mentioned their “church family” was a key component of thriving for them.

Theme 2: Personal Strengths/Resources

Participants described a range of personal qualities, interests, and skills that helped them navigate daily life and promote their own thriving. These strengths included maintaining a positive attitude, engaging in hobbies that brought enjoyment and structure, and participating in advocacy and self-advocacy efforts. Together, these resources contributed to the identities and wellbeing of both groups.

Positive Attitude

Both groups emphasized the importance of maintaining a positive attitude in thriving, highlighting how mindset can shape day-to-day experiences and long-term well-being. For people with IDD, this often showed up in small, joyful moments and in the emotional presence of supportive relatives. One participant shared, “my dad makes me laugh every day,” suggesting that daily humor and connection were powerful sources of joy and resilience (M.S., Participant with IDD). Another reflected on how emotional support from a caregiver gave her hope, saying, “for me, it's having my mom by my side and knowing that even though I'm having a tough day, that my day’s only going to get brighter as my day goes on” (B.J., Participant with IDD). These statements reflect an outlook grounded in optimism, trust, and emotional security.

Family caregivers also spoke about the value of intentional positivity, especially when navigating complex or ongoing challenges. One caregiver shared, “you cannot choose what happens to you, but you can choose how you're going to deal with it,” underscoring the role of perspective in facing challenges (E.M., Family Caregiver Participant). Another caregiver offered a more lighthearted but strategic take: “to thrive is a sense of humor and picking our battles, find what hill you're going to die on, and which one you’re not going to” (L.M., Family Caregiver Participant). Collectively, these quotes speak to the role of humor, perspective, and emotional resilience as not just coping mechanisms, but essential ingredients for thriving.

> “I always tell my daughter …we have to have fun in this process. So we have to look at the possibility and the positive of this.
>
> —C.A., Family Caregiver Participant

Hobbies

> “What helps me thrive is music… little bit of poetry.
>
> —P.J.W., Participant with IDD

Participants with IDD were more likely than family caregiver participants to report hobbies as an important part of thriving. One participant with IDD mentioned “playing with your dog, running outside, hanging out with your friends…” (G.C., Participant with IDD), while others mentioned listening to music, attending sporting events, going to Walt Disney World, fishing, and drawing.

In contrast, family caregivers seldom mentioned their own hobbies, but would mention their family member’s interests, especially if those interests help the individual form more social network connections. One family caregiver, whose son was blind, explained that he had not considered taking his son to a baseball game because of his disability. On an occasion where his other (sighted) sons were unable to attend, he invited his son to a game together. The father said, “he could not see the game or understanding, but he enjoyed buying the popcorn and the soda” (E.M., Family Caregiver Participant). This became an enjoyable activity they could share together.

A less frequently cited source of thriving was health and exercise. One participant with IDD explained how his mother helps him to make healthy eating decisions. Others described walking, biking, or running. When exercise was mentioned, it was often coupled with other social activities, including competing in Special Olympics. Multiple participants mentioned Special Olympics programs as a source not only of exercise, but also of friendship and comradery.

Advocacy

As part of the Supported Decision Making (SDM) discussion, both groups discussed family members' role in providing advocacy for the person with IDD. They also described a nuanced role for the family member or guardian to guide and train the person with IDD to become more autonomous and independent.

People with IDD described guardians and family members as essential advocates, especially when they faced situations where they could not fully advocate for themselves. One participant explained that a guardian's role is "to make sure that you are advocated—when you can't advocate for yourself" (P.J.W., Participant with IDD). These participants with IDD emphasized that advocacy should not replace their voice, but should support them until they could speak for themselves. Another participant explained that he had just finished a discussion with his mother where addressed "whenever you have a disability… you always have rights and responsibilities (A.H., Participant with IDD). When the researcher followed up about the participants' understanding of his 'responsibilities,' he responded, "to be responsible for your own self advocate" (A.H., Participant with IDD). These responses suggest that advocacy from parents should be an empowering, transitional role.

> "[Parents/Guardians] have to kind of train you how to be a guardian for yourself…"
>
> —P.J.W., Participant with IDD

Several participants with IDD also highlighted the goal of learning self-advocacy skills through family support. As P.J.W. put it, "your parent is kind of helping you, teaching you along the way how to advocate for yourself...but if you can't, that's okay, then you have other people around you to help" (P.J.W., Participant with IDD). The understanding of advocacy as something which coexists with efforts to build independence was a consistent theme across the focus groups for people with IDD.

Family members similarly viewed advocacy as a critical part of their role, but emphasized the importance of fostering growth and independence, even when that involved risk or struggle. One family member reflected on the value of letting their relative learn through experience: "if you diminish their experience, whether that's them picking out what they want to order at a restaurant, or seeing them struggle doing something...the end result is going to be a person that's resilient" (T.W., Family Caregiver Participant). Others discussed the personal challenges of stepping back to allow independence. One family member said, "I have to control and make sure I'm not setting the limits. I have to let go and let her take the fixed route bus. I've got to let her change airplanes...” (B.F., Family Caregiver Participant). In listing various activities which her child may be able to accomplish independently, this family member is emphasizing the balance between ensuring safety and encouraging autonomy. Family members positioned advocacy not just as protecting rights and opportunities in the moment, but as deliberately creating space for self-advocacy and resilience over time.

Both groups understood advocacy as not just speaking up on someone’s behalf, but more holistically as building the skills, confidence, and opportunities for people with IDD to advocate for themselves whenever possible. People with IDD focused on needing support until they could become self-advocates, while family members emphasized their responsibility to gradually step back and allow independent decision making. Across both groups, advocacy was framed as a dynamic, evolving process rooted in trust, teaching, and respect.

Self-Advocacy

Participants with IDD were more likely to describe self-advocacy as an important part of their ability to thrive. This theme often overlapped with the related concept of autonomy and self-determination, which will be explored in more detail in the following section on housing, employment, and independent living. Self-advocacy was discussed both as a personal trait, expressed through making independent choices, and as a formal activity, such as participating in a self-advocacy group. Many participants with IDD expressed pride and a sense of self-worth through these actions, whether by asserting their preferences in daily life or engaging in organized advocacy efforts.

Theme 3: Decision Making Supports

Families played a central role in the thriving of people with IDD, and both caregivers and individuals with IDD extensively discussed the interconnected roles and needs related to decision making within their family systems. This section explores the critical role that family members, guardians, and other supporters play in assisting individuals with IDD in their decision-making across key areas of life. From helping navigate financial choices to making medical and safety-related decisions, the support provided is essential for ensuring that individuals can make informed, autonomous decisions.

The following subsections outline the various forms of support that guardians or family members may offer in these important areas: supported decision making, financial support/financial decision making, medical care/medical emergencies, and safety/protection of the individual with IDD.

Supported Decision Making

In the legal sense, Supported Decision Making (SDM) refers to an approach that empowers individuals with IDD to make their own decisions with the assistance of trusted supporters, rather than having decisions made on their behalf through guardianship (American Bar Association, 2017). While several participants in the family café focus groups did reference the legal definition of SDM, their understanding of the legal definition was tenuous. As such, this theme primarily algins with a more informal definition of supported decision making. For both people with IDD and family members, SDM was seen as a way to maintain autonomy while providing necessary guidance, but their perspectives emphasized different concerns and experiences.

For participants with IDD, SDM was described as a way to receive guidance while remaining in charge of their own lives. Family members were seen as important advisors, not decision-makers. One participant explained that family helped by "helping me weigh out the facts...help me think about it a little bit more in depth" (P.J.W., Participant with IDD), illustrating how support was about encouraging careful, independent choices. Another participant emphasized that a guardian's role in their life was “showing you how to live on your own” and "showing you how to respect other people" (D.M., Participant with IDD), focusing on skill-building and personal growth rather than control.

> "So guardianship is important...you need someone to be a guardian for you until you're able to do it yourself, if you are able. But they have to kind of train you how to be a guardian for yourself.”
>
> —P.J.W., Participant with IDD

Family caregivers also valued preserving autonomy, but described the emotional complexity of deciding when to intervene. One caregiver expressed deep conflict over guardianship decisions: "I didn't want to take rights away...it made me cry when I signed that paperwork! But it was about her protection and that I didn't understand that at first” (N.W., Family Caregiver Participant). Others reflected on their ongoing uncertainty about how much authority was appropriate. One sibling who was deciding whether to pursue guardianship for her sister that was living with her said, "I'm still learning about that...is it every single thing in her life that I'm gonna be over?" (L.B., Family Caregiver Participant). These caregivers' emphasis on protection and safety for their family member is described in further detail in the subsection below.

Financial Support/Financial Decision Making

Both people with IDD and family members described financial decision making as a key area where family advocacy plays an important role. However, the tone and focus of their comments differed slightly between groups. Participants with IDD discussed how their families guide them in making responsible financial choices without fully taking over. One participant explained that their parents help them learn how to manage a credit card: "they'll show me how to use my card...make sure I don't give anybody the card number" (M.H.G., Participant with IDD). This participant emphasized that financial decision making is a collaborative process: “that’s between me and my mom. So, she helps me with my money...we have a conversation” (M.H.G., Participant with IDD). Participants described needing support with managing financial decisions when they have limited funds. One participant described this by joking about how expensive the food from hotel room service were at the Family Café conference. He explained that before buying the item, he would “… ask somebody that you trust, because your stomach is saying, ‘I want food’ … But in reality, you're kind of— sixteen dollars??” (P.J.W., Participant with IDD).

Family members were more likely to focus on managing financial risk and ensuring stability. Some described taking formal legal steps to maintain control over funds without pursuing full guardianship over property. One family member shared, “I am representative payee. I keep all the credit cards...we chose not to do the guardianship of the property...because that's a lot of headache and a lot of extra paperwork” (B.F., Family Caregiver Participant). Another family member highlighted the difficulty of balancing control with fostering independence, noting that their daughter became frustrated because "she can't go to the bank and talk about her bank account...they're gonna only talk to me" (V.G., Family Caregiver Participant).

Medical Care/Medical Emergencies

Participants from both groups also underscored the crucial role of family members in advocating during medical emergencies, particularly when individuals with IDD might not be able to communicate effectively with healthcare providers. Both groups seemed to reach consensus on the necessity of this type of support in helping them to thrive. One participant with IDD explained, "if you're in the hospital...you're in a coma...you have to have somebody to advocate for you, because you can't do it" (PJW, Participant with IDD). Another reinforced this idea, emphasizing that guardianship is necessary so that you can have “someone to make decisions for you if you can’t” (L.J., Participant with IDD).

In one case, a family member described a situation where her daughter was in the hospital, and she sought emergency guardianship. Her daughter, who has Down syndrome, was being asked to make medical decisions. According to the family member’s testimony her daughter’s doctor was not consulting with a cardiologist about her care and her daughter was unable to advocate for that herself. After seeking emergency guardianship during that hospital stay, the family member explained “I said, over my dead body, yeah, you're cutting anything of her without having the [cardiologist's approval]" (J., Family Caregiver Participant).

Other family members discussed real-world experiences where medical advocacy had been vital, though more commonplace. One described frustration when medical professionals insisted on speaking directly to their son, despite his inability to communicate: "the kid doesn't speak. He's almost dying, and you're going to wait and do whatever you want" (E.M., Family Caregiver Participant). Another family member recounted trying to help their daughter communicate more effectively with doctors, explaining, "she goes to the doctor on her own...but when she has a problem, she comes to me" (V.G., Family Caregiver Participant), highlighting the tension between promoting independence and ensuring complete, accurate communication.

> ""[My son] is vulnerable to financial manipulation, making decisions, so I just want to be able to protect him.
>
> —J.S., Family Caregiver Participant

Across both groups, participants emphasized that having a guardian, caregiver, or trusted advocate present during medical emergencies was not simply helpful, but essential. Without strong advocacy, individuals with IDD risked receiving inappropriate or even dangerous medical care, particularly when they could not clearly express their needs. This type of advocacy was consistently described as critical to ensuring both immediate safety and long-term well-being, reinforcing its central importance to thriving.

Safety/Protection of Individuals with IDD

Safety and protection emerged as broader, ongoing concerns in family caregivers' discussions. While people with IDD did reference a desire for safety during medical emergencies (as described above), broader conversations about daily safety were much less frequent among the focus groups with people with IDD. This reflects a difference in perspective between the two groups: while people with IDD felt a great need for autonomy and control, family caregivers' responses reflected a tension between wanting to respect their child's autonomy and fearing that without guidance, the person with IDD could be vulnerable to serious risks.

Family members spoke candidly about the difficulty of ensuring protection across many aspects of their family member's life. One caregiver described the challenge of finding "a safe place to get him plugged in," emphasizing that their son was "too vulnerable and naïve" to navigate some environments independently (L.M., Family Caregiver Participant). Another highlighted how deeply safety concerns shaped their daughter's daily experience, explaining, "for her, the primary thing is, 'Am I safe?' and she says it

50 times a day" (N.W., Family Caregiver Participant). Some family members also worried about legal vulnerabilities, such as the risk that someone could exploit their child's trust: one parent reflected, "[My son] is vulnerable to financial manipulation, making decisions, so I just want to be able to protect him. I mean, he can vote, but, you know, financial and big decisions are up to me" (J.S., Family Caregiver Participant).

Many parents referred to the person's vulnerability and limited capacity to make wise decisions. As one family member described it, "he doesn't understand abstract things… he's gonna make teenager decisions" (M.M., Family Caregiver Participant). Another explained initially resisting guardianship because it felt like "taking rights away," but later realized that without legal protections, "someone could mislead her and literally marry her and she wouldn't know what was happening" (N.W., Family Caregiver Participant). This shows how their motivation for stepping in was not about controlling everyday choices but about preventing exploitation. Overall, family members' comments made it clear that their support for guardianship or SDM was not simply about control. It was rooted in profound fears about safety, including the risk of exploitation, misunderstanding, or harmful mistakes if the person with IDD were required to manage all decisions independently.

However, there seemed to be some conflicting ideas about this balance of safety/autonomy between family members and people with IDD. People with IDD rarely initiated conversations about their personal safety outside of medical emergencies. One participant did raise concerns about interactions with police, emphasizing the importance of guardianship to help in such situations: "I don't think every cop has been trained on [developmental disabilities], and they should have been" (B.J., Participant with IDD). Outside of these few instances, safety and protection were not central themes for people with IDD.

Together, these findings suggest that while people with IDD recognize and value protection in specific high-risk contexts like medical emergencies, family members experience safety and vulnerability as pervasive, ongoing concerns that influence many areas of decision making and planning.

Theme 4: Supports for Independent Living

This section explores how housing, employment, and independent living opportunities for people with IDD contribute not only to their own thriving, but to the thriving of their entire families. As with other sections in this report, both family caregivers and people with IDD emphasized that what supports one individual's success and independence has ripple effects that significantly impact the well-being of the whole family.

Subsections highlight specific areas where participants identified challenges and opportunities, including Autonomy and Self-Determination; Employment for People with IDD; Employment Limitations for Family Members; Activities of Daily Living; Independent Living Aspirations & Independent Living Communities; and Housing Affordability.

Autonomy and Self-Determination

Autonomy and self-determination were among the most frequently discussed and important themes across both family caregiver and people with IDD focus groups. Participants consistently emphasized that the ability to make decisions, pursue goals, and live independently was a crucial element of thriving.

This strong emphasis in the focus groups mirrors broader findings in the disability literature, which highlight autonomy and self-determination as key predictors of quality of life, mental health, and long-term outcomes for people with intellectual and developmental disabilities (Lachapelle et al., 2005; Mumbardó-Adam, Vicente, & Balboni, 2020). The experiences and aspirations shared by participants reinforced the critical role that fostering autonomy plays in enabling individuals and families to thrive.

Both family members and people with IDD valued autonomy, but they sometimes described it from slightly different perspectives. People with IDD spoke about autonomy primarily in terms of desires for independence and pride in personal decision-making. One participant shared their goal of living independently, saying, "I really want to own my own [house] someday...I'm just trying to make my parents proud" (M.H.G., Participant with IDD). Others emphasized daily decision-making, with one person asserting simply, “I make my own choices” (K.S., Participant with IDD). Participants with IDD framed self-determination as something they both aspired to as well as part of how they were currently living.

Family members were more likely to frame autonomy in terms of the dignity of risk for their child. Caregivers spoke about consciously allowing their relatives to face challenges, even when it was difficult. Another family member emphasized the importance of balancing safety concerns with the need for growth, describing a conscious decision to "allow them to fly" rather than "closing their world in," even while acknowledging the risks involved (T.W., Family Caregiver Participant).

> I think of thriving in terms of my son as independence.
>
> —L.H., Family Caregiver Participant

Both groups recognized that self-determination was not only about isolated moments of independence but about ensuring that the person with IDD's life includes real choices as well as community participation. A family member described their daughter's thriving experience in an independent living home, highlighting that she was "living [his] best life" with friends, activities, and autonomy over her daily routine.

For people with IDD and their families alike, autonomy and self-determination were portrayed as deeply tied to dignity, thriving, and a fulfilling life. Self-determination was seen as a fundamental need. Families were able to thrive when the person with IDD was empowered to live as independently as possible.

Employment for People with IDD

As noted in Table 3, less than half of the focus group participants with IDD were employed. Participants with IDD who were employed spoke about their job as a critical source of identity, pride, and independence. Several individuals shared their enthusiasm for working, with one participant expressing, "I have a job, I've got two jobs, I'm trying to focus on work" (P.M., Participant with IDD). Thriving was closely tied to the opportunity to work, contribute, and exercise autonomy in their lives. Family members similarly recognized the importance of employment for the well-being of their family member, emphasizing that while the financial compensation was often minimal, employment helped their family member with IDD to find meaning and support.

> "Giving him the opportunity to work as a greeter, I think helps him thrive…I think it's been great for his self-esteem, his confidence, and how he interacts with people."
>
> —J.S., Family Caregiver Participant

Family members also frequently highlighted barriers to employment. Family members expressed concerns about the availability of appropriate opportunities, workplace accommodations, and vocational rehabilitation programs. Family members emphasized structural challenges and the need for systems that ensure stability and fairness in employment opportunities for people with IDD.

Employment Limitations for Family Members

While occurring less frequently, family members sometimes expressed a related concept, describing ways in which their caregiving responsibilities limited their own employment opportunities. Many expressed that providing care for their family member with IDD often forced them to leave the workforce entirely, reduce their hours, or turn down career advancement opportunities.

> "[My sister with IDD] ha[s] days where, you know, the caretaker may say, “Hey, you got to come home.” That mean-- that's half a day at work.”
>
> —L.B., Family Caregiver Participant

Caregivers described feeling stuck in jobs that allowed for greater flexibility rather than pursuing roles that would have better pay or career growth, simply because flexible hours were necessary to accommodate caregiving duties. Several participants also reflected on the emotional toll of these decisions. Caregivers described a sense of sacrifice, frustration, and loss associated with limiting or ending their careers. One caregiver noted the financial precarity that these employment limitations created, affecting not only their current household income but also their future financial security, including retirement savings. In one particularly poignant moment, a family member described how she was working two jobs, which means that she is not available to provide transportation for her son during the day to activities which might help him to thrive. She explained: “There have been a ton of resources [at the Family Café conference] that all sound fantastic. And they all tell me I have to quit two jobs to get him where he needs to be, to make him thrive, to help him thrive. He has to be 100% of the focus” (L.M., Family Caregiver Participant).

These employment limitations reveal a major barrier for family caregivers’ ability to thrive, as well as the people with IDD themselves missing out on opportunities. Thriving is not just about ensuring the well-being of the person with IDD; it also requires systemic support that allows family members to maintain meaningful employment if they choose. Without greater flexibility, respite services, or policy protections, family caregivers are forced to make difficult trade-offs that ultimately undermine their own well-being and economic stability.

Activities of Daily Living

While less prominent than other codes within the “Support for Independent Living” theme, several participants with IDD mentioned support with activities of daily living (ADLs) as important to their thriving. Family caregiver participants also sometimes described supporting their family member with activities of daily living, but seemed more focused on supporting autonomy or broader life activities rather than daily tasks alone.

People with IDD often described ADL support in practical terms. One participant emphasized that the need for support "if you get stuck in...doing a chore or whatever, you ask them for help" (T.S., Participant with IDD). Others expressed a wish for guardians to assist more with basic household tasks, like “making our dinners, our breakfasts, our lunches, helping us pick out healthier snacks” (B.J., Participant with

IDD). Assistance with chores like cooking, cleaning, and trash removal was framed as part of feeling supported and loved.

Family members, on the other hand, referenced activities of daily living in the context of promoting normalcy and life skills. One caregiver shared that their daughter enjoys doing laundry independently, describing it as a piece of "normalcy" (K.E., Family Caregiver Participant). Another family member reflected on balancing skill-building with moving forward in broader life goals, explaining that focusing on chores like folding clothes was part of daily life, but not the sole emphasis. Some caregivers also mentioned offering targeted help with hygiene or appointments when needed, while encouraging as much independence as possible.

While ADL support was acknowledged as important, discussions about it were relatively limited compared to other themes related to Supports for Independent Living.

Independent Living Aspirations & Independent Living Communities

Both people with IDD and their family members consistently expressed that independent living, particularly in terms of housing, was an important part of thriving. Participants with IDD talked about their hopes of living on their own, having their own space, and managing daily life outside of their family home. One participant emphasized that thriving meant "getting on your own. Get your own place," (K.S., Participant with IDD) while another shared that learning skills like cooking and cleaning were important steps toward eventually living in an apartment or shared community setting. Their comments reflected a strong desire not just for independence in decision-making, but specifically for independent housing arrangements.

Family members strongly supported these aspirations, recognizing that independent living is central to their family members' thriving. However, they also emphasized the importance of safe, supportive environments that could make independent living sustainable. Families often sought models that offered autonomy while still providing needed support. Independent living communities were highlighted as successful examples of how this balance can be achieved. One family member described independent living communities as ideal environments where adults with IDD could live semi-independently, with access to peer relationships, social engagement, and structured support. The model offered her peace of mind, knowing her daughter could thrive both socially and practically in this setting.

Housing Affordability

Participants with IDD often mentioned the unaffordability of housing as a key barrier to independent living. When asked what Florida programs and policies might help him thrive, one participant explained “I would say we need to put more money into affordable housing that way more people have more options of where to go. Because the options are not that good” (M.S., Participant with IDD).

Family caregivers similarly referenced the cost of living for their children, but were more likely to talk about the cost of hiring paid caregivers in addition to the cost of housing itself. One family member remarked, “we're both so thankful for Med Waiver, because there's no way we could afford $3,500 a month at a group home” (S.H., Family Caregiver Participant).

Theme 5: Formal Supports/Services

While informal supports from family, friends, and community networks play a vital role in helping individuals with disabilities and their families thrive, formal support service systems are equally critical. These systems provide the structured, essential services that many families cannot access elsewhere. Without access to government programs and other formal supports, many families face unsustainable financial burdens, limiting both their own well-being and the opportunities available to their family member with a disability.

In this section, we explore key aspects of the formal support system, including Government Programs/Support; In-Home Caregiving; Experience of Precarity with Formal Systems; Transition from High School to Adult Service Systems; Navigating Service Systems; Disparities in Services Based on Counties of Florida; Transportation; Future Planning; Respite; and Non-Government Support Programs for People with Disabilities.

Government Programs/Supports

Families of people with IDD frequently reported they rely on government programs such as Medicaid waivers (Med Waiver), Supplemental Security Income (SSI), and vocational rehabilitation (VR) to access the services and support they need to thrive. Participants shared that while these programs can be critical lifelines, the reality of accessing and navigating them is often frustrating, inequitable, and burdensome. Even after securing these support, families described gaps and challenges that continue to threaten their stability.

A central theme across participants' experiences was that government supports, ***when they work***, truly help families thrive. However, getting them to work often requires persistence, privilege, and, at times, sheer luck. As two caregivers described, in a back-and-forth exchange:

> “**C.S.**- So when the services work, they work.
> **L.H.**- They work.
> **C.S.**- They work well.
> **L.H.-** When they're there.
> **…C.S.**- we're on the waiver. And when it works, it works amazing." (C.S., Family Caregiver Participant & L.H., Family Caregiver Participant)

Others compared the Medicaid waiver to "Willy Wonka's golden ticket," acknowledging that while it "doesn't answer all your problems," it opens doors to critical resources otherwise inaccessible (T.W., Family Caregiver Participant).

Families overwhelmingly reported systemic barriers to accessing supports. Long waiting lists, confusing eligibility criteria, income thresholds, and administrative mistakes limited access to the support families needed to thrive. One caregiver captured the frustration of the system’s design: “Med Waiver and APD and things like that… we just don't qualify because, like you said, we make this much money, and he doesn't risk losing his home, so he's not at risk. We've been on the list since he was 18, and he's 27” (L.M., Family Caregiver Participant). Another summed up the sentiment bluntly: “It makes it so hard—you’re trying to do the best for your child and your family, and doors are shutting in your face” (V.G., Family Caregiver Participant).

Even once families are approved, programs do not always function as promised. Families reported administrative errors, poor communication, and inconsistent delivery of services. A caregiver reflected on their experience with vocational rehabilitation: "I had to go after vocational rehabilitation to get services, and they change counselors, they write a plan, and they don't follow up. They don't call me. My daughter is not going to do it on her own, so making her able to work depends solely on the time availability and responsibility of caregivers around—that's why it’s so hard" (J., Family Caregiver Participant).

Many discussed the process of getting support difficult sometimes and described that they had to "fight for the services" (J., Family Caregiver Participant) which their family member should be entitled to. Many recognized their own privilege in being able to navigate these complex systems, with one caregiver noting, "I'm good enough to

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“People are always talking about where Social Security stands. Is Social Security going to stay?... Is Medicaid going to go bankrupt?... this is always in the news, and it’s always on the table, and it’s kind of scary, because when you are in the situation we’re in, that we really need it, it’s concerning.”

—F.D.M., Family Caregiver Participant

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manage my way in the system to get the support from the system, somehow it's easier because I could get paid support...but not everybody is as lucky" (J., Family Caregiver Participant).

Family members also frequently reported concerns about financial sustainability of government programs. Families who rely on SSI and Medicaid expressed anxiety about future cuts or instability. As one participant shared, “People are always talking about where Social Security stands. Is Social Security going to stay?... Is Medicaid going to go bankrupt?... this is always in the news, and it’s always on the table, and it’s kind of scary, because when you are in the situation we’re in, that we really need it, it’s concerning” (F.D.M, Family Caregiver Participant).

Throughout focus groups, families emphasized a broad belief that society has a responsibility to ensure these government programs for people with IDD are strong and accessible. As one caregiver explained, “It might be costly to the state to maintain programs like the programs that my family benefits from, but it's not our fault that we have a disabled person. Society should protect those that need it the most” (J., Family Caregiver Participant).

In-Home Caregiving

Both participants with IDD and family members discussed the role of in-home caregiving in their lives, highlighting it as a crucial support for helping families and individuals with IDD thrive. For many families, in-home caregiving services provided vital support that allowed family members to balance caregiving responsibilities while also managing other aspects of daily life. Family members described how having someone assist in the home with daily living tasks, personal care, or supervision gave them much-needed relief and helped their family function more sustainably. This was discussed in more detail earlier in this report in the section on “respite.”

People with IDD also acknowledged the value of in-home support, particularly when these services helped them maintain a higher degree of independence and comfort in their own homes. In-home caregivers could help with tasks like cooking, cleaning, and medical management, allowing individuals with disabilities to live more fully in their chosen environments rather than moving into institutional or group settings.

However, both groups also identified significant challenges with in-home caregiving. Access to consistent, high-quality in-home support was not guaranteed. Participants noted issues such as long waitlists, shortages of trained staff, and variability in the quality of caregiving services. Some family members expressed concerns about trusting caregivers or about the disruption caused when staffing changed frequently. They described difficulty securing reliable, well-trained in-home supports.

> " I became my daughter's provider of personal supports because it was always hard to find someone that would do that job appropriately in your home…"
>
> —J., Family Caregiver Participant

Experience of Precarity with Formal Systems

Participants in both groups, but particularly family members, highlighted how fragile their current support systems feel and the stress of planning for an unpredictable future. *Precarity* refers to living with ongoing uncertainty and instability. Families often felt their situations were precarious, and basic needs like housing, healthcare, and support services are not guaranteed to continue. Many participants described how this constant sense of risk shaped both their daily lives and their long-term planning for stability and care.

Government programs and their precarity were a frequent source of stress and uncertainty. For instance, SSI was seen as vital but precarious. Family members struggled with bureaucratic errors, such as missing paperwork or difficulties finding banks familiar with setting up representative payee accounts. While some family caregivers had positive experiences with vocational rehabilitation, one family member reported, “there’s a lot of information around about the wonders that vocational rehab would do. I haven’t seen it. I haven’t seen it,” a caregiver emphasized (J., Family Caregiver Participant).

Income and asset limits within Medicaid and SSI were a consistent concern. Families discussed how even small amounts of earned income could jeopardize benefits: "With SSI, they—you want them to be independent. But okay, if you make $80 a month, we're going to reduce your benefits" (M.S.2, Family Caregiver Participant). Another participant with IDD shared that “when you work a certain amount of hours, you lose your benefits, and I wish that Florida could change that. Could change the verbiage of that so people with disabilities can work, you know, as much as they want without having to lose their benefits” (M.H.G., Participant with IDD). Several other members of the focus group nodded their head in agreement with this comment about the importance of being able to work without fear of losing necessary benefits. This illustrates how working toward greater independence can paradoxically make someone more financially vulnerable. In a similar case, the mother of a young woman who was thriving within her independent living community expressed concerns about her daughter's increased autonomy being a threat to the very benefits that ensured that autonomy in the first place. She explained, "one problem that we're having now is [daughter's name] is thriving through all her services. So, SSI wants to deem her as not disabled anymore…. but she's not independent! Cuz she's dependent on all these services!... so, if they drop her, then we lose all our services. So, they want to deem her not disabled, but she can't live without [those services]" (C.S., Family Caregiver Participant).

> "[My daughter] is thriving through all her services. So SSI wants to deem her as not disabled anymore…. but she's not independent! Cuz she's dependent on all these services! So they want to deem her not disabled, but she can't live without [those services.]"
>
> —C.S., Family Caregiver Participant

Medicaid Waivers were also widely viewed as crucial, but only for those fortunate enough to gain access. Several family members whose children were receiving the Med waiver reported that only happened because of a crisis, as one mother reported "I was going through chemo myself, when, when [son's name] was-- it was an emergency situation and he got put on the Med Waiver" (S.H., Family Caregiver Participant). As another caregiver put it, "We have those who would do anything in the world to get on the waiver" (C.S., Family Caregiver Participant). Yet the waitlists, eligibility restrictions, and uneven service availability continued to make the waiver feel out of reach for many.

Across both groups, the experience of precarity was not just about economic insecurity but about the emotional toll of living with instability. Planning for the future felt daunting when even the present-day supports felt unreliable, and participants voiced a shared desire for stronger, more dependable systems to help safeguard the well-being of people with disabilities and their families.

Transition from High School to Adult Service Systems

A small subset of responses about precarity in the lives of families of people with IDD related to the impact of leaving the school system and entering the adult service system. Families described the transition as a time when existing supports suddenly disappeared, leaving them struggling to find new services in a much less coordinated environment. One family caregiver reflected, "Once they're out of the school system.., you have to find everything on your own" (M.S.2, Family Caregiver Participant).

Participants also emphasized how difficult it was for young adults with IDD to maintain structure, purpose, and social engagement once school ended. As one person with IDD shared, "Now this is hard… I miss all my friends… I used to go to school… I want to get back [to school]. It's my favorite thing to do, I want to go back to say goodbye to them" (P.M., Participant with IDD). The transition to adulthood, intended to be a time of greater independence, often instead created a deep sense of loss and instability for both individuals and their families.

Navigating Systems

A broader theme among participants was the challenge of navigating adult DD support systems. While government programs provide important support, as described in an earlier section, families and people with IDD also emphasized the broader, ongoing challenge of navigating adult disability service systems. Participants described a fragmented, confusing landscape where access to services often depended less on need and more on a family's ability to persistently advocate, organize, and troubleshoot without clear guidance. This constant work of navigation was a major factor in whether families and individuals could truly thrive.

Thriving was possible, participants shared, when families were able to piece together the right combination of services, healthcare providers, housing, transportation, and employment supports. However, the burden of building and maintaining access to support systems typically fell entirely on individuals and their families. Some highlighted the relentless logistical challenges, from coordinating multiple service agencies to managing basic transportation needs. One participant with IDD shared, "I have to get up twice a week at 6:30 in the morning to catch a bus to get where I need to go," illustrating the extra burdens she has to endure just to meet basic needs (B.J., Participant with IDD).

> "…everything is so compartmentalized…"
>
> —N.W., Family Caregiver Participant

Participants described a service environment where responsibility was diffused across many systems, including medical, educational, employment, housing, and transportation. These different service systems often have no way of communicating with one another, and families have to try to do this coordination alone. Even tasks as fundamental as finding a doctor or understanding insurance coverage required intense effort: "It's hard for me to figure out when I need to actually be in there [at a doctor's appointment" (B.J., Participant with IDD). The lack of coordinated systems meant that those without strong advocacy skills, resources, or time often fell through the cracks.

> "…it's like swimming in the dark…"
>
> —J., Family Caregiver Participant

Navigating adult systems was not only a logistical burden but an emotional one. Families and individuals with IDD expressed anxiety and frustration about missing opportunities, misunderstanding eligibility rules, or being left behind by systems that were supposed to support them. Rather than designing systems that are accessible and equitable by default, the burden of securing services is shifted onto individual families. This forces families to navigate complexity, advocate ("fight for services"), and absorb the consequences when there are systemic failures. As a result, thriving often depended not only on the needs or strengths of the individual with IDD, but also on the resources, knowledge, and persistence of their family. This often leads to inequitable outcomes. Those with greater financial means, social capital, or familiarity with the system seemed to succeed, while others faced isolation, instability, or unmet needs.

Disparities in Services Based on Counties of Florida

For families, part of describing the process of navigating adult services was a discussion of how service disparities exist based on the county of Florida you live in. Participants emphasized that even when families tried to access the same state programs, the level of available services and the number of providers varied across counties. One family caregiver shared, "Where we live in Okaloosa County—there are no services [for adults with disabilities]" (S.H., Family Caregiver Participant). Similarly, a participant described having to know "what hoops to jump through," but after moving to a Bradford county, their family say an even steeper drop in available services, citing "small county syndrome. [They have] nothing" (K.E., Family Caregiver Participant). Another noted that county differences had a major impact on available opportunities: "She's in Orange County. It makes a big difference. They have a lot more than we do here" (L.M., Family Caregiver Participant). These disparities meant that thriving was not only about individual effort but also about geographic luck, with families in some areas facing far more limited options than others.

> "Where we live in Okaloosa County—there are no services [for adults with disabilities.]"
>
> — S.H., Family Caregiver Participant

People with IDD noted similar disparities, particularly in reference to accessing transportation. Participants shared that transportation services were inconsistent or unavailable depending on where they lived, creating additional barriers to independence and participation. One person with IDD explained, that paratransit and other accessible transportation services vary by county. Another highlighted broader service gaps beyond transportation, saying, "[transportation] for [Sarasota] county is disgusting…. SCAP plus takes forever" (B.J., Participant with IDD). The lack of reliable transportation options in certain counties made it harder for people with IDD to access jobs, healthcare, education, and community life, directly limiting their ability to thrive.

Beyond service availability and transportation, participants also noted disparities in advocacy and attention from local officials. In some counties, families felt supported because of active local organizations or government offices more familiar with disability issues, while others described being overlooked. These differences reinforced the sense that outcomes for people with IDD in Florida are not only shaped by their needs or efforts but also by where they happen to live, which participants viewed as unfair.

Transportation

Across both types of focus groups (people with IDD and their family members), there was clear and consistent agreement: lack of reliable transportation is a major barrier to thriving. Participants emphasized that without dependable ways to get to work, school, healthcare, or community activities, opportunities for independence and inclusion are incredibly limited.

People with IDD frequently described the constraints they faced when public or accessible transportation was unavailable. One participant explained, “I have to agree with [other participant] with the whole transportation thing,” signaling widespread frustration within the group (T.S., Participant with IDD). Another noted, “We have four areas you call for transportation, they take forever,” (M.S., Participant with IDD) illustrating the challenge of maintaining community engagement because of transportation delays.

Family caregivers highlighted how inaccessible or absent transportation options left them responsible for all driving, which in turn limited employment and respite opportunities for caregivers themselves. A family caregiver participant explained ““Getting… special transportation services in the county is difficult. It's not easy. You had to fill out a form by the doctor, schedule at least 24 hours in advance, pickups and drop off. They don't show up on time, they will leave the person out there. So, **I gave up on getting that service**, because I'm able to drive. Eventually she might need it” (J., Family Caregiver Participant).

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—J., Family Caregiver Participant

The systemic and structural barriers caused by the lack of transportation options for people with IDD directly impacted their ability to thrive. Without dependable ways to get around, individuals with IDD and their families were cut off from work, recreation, social connection, and even basic healthcare access. This broad consensus across both groups points to the urgent need for more accessible, affordable, and reliable transportation systems if people with IDD are to truly thrive in their communities.

Future Planning

Having future plans in place was described as a key component of thriving for some families within the focus groups. Several family caregivers expressed a sense of relief and empowerment after receiving training or support related to long-term planning for their child with IDD. One caregiver shared that she had participated in a future planning intervention through The Arc Jacksonville, which helped her begin preparing for her child's entire lifespan, including arrangements for after her own death. The participants' recommendation of this program to the rest of the group revealed that thriving involves not only managing current needs, but feeling secure for the future.

> Another huge thing looking forward is when I'm not here, I don't have family members. I don't have anyone to care for her. And I had her late in life, and so recognizing that a third party person is actually going to have to take over this project is just a whole other layer of where you like hire companies to make decisions on behalf of protecting her, because there's just no close people.
>
> —N.W., Family Caregiver Participant

Future planning was also a major motivator for attending the Family Café conference. Some participants came specifically for sessions on legal and financial planning, eager to connect with attorneys and professionals who could help them establish trusts or long-term support plans. One parent stated, "this is my goal this weekend, I have got to establish a trust fund…" and went on to describe her deep fear of her child being placed in an inappropriate group home after her death, saying "to have him in one that's not going to warehouse him. I have to try and find family. Will you please come and take him out for Christmas? Will you please come out and take him up-- you know?" (L.H., Family Caregiver Participant). This echoes the broader anxiety shared by many caregivers about what would happen to their children when they were no longer around to advocate and provide.

> “I'm going to die, and what is my son gonna do?”
>
> —L.H., Family Member Participant

Another caregiver reflected on a similar situation, sharing that she had no close family members who could step in to care for her daughter and had her child later in life, saying “I don’t have anyone to care for her” (N.W., Family Caregiver Participant). This realization prompted her to explore the use of third-party companies or legal entities to take over guardianship and decision-making responsibilities. Her laughter, tinged with anxiety, hinted at the enormity of the task and the emotional complexity of planning for a future that feels both necessary and out of reach.

Future planning also often involved consideration of siblings, who were seen as likely to take on caregiving or decision-making responsibilities in the event of a parent’s death. Some family caregivers expressed a desire to shield their other children from the burden of future care planning by taking proactive steps themselves. One caregiver reflected on her own unfinished preparations, saying, “haven't done a will yet, but I know it's necessary. I know that I should, I shouldn't have something arranged already, so I won't let my other kids with the responsibility of planning what to do with me or with my daughter” (J., Family Caregiver Participant). His comment reflects not only a sense of personal responsibility, but also the emotional weight many parents carry in trying to protect all of their children, including the child with a disability as well as their siblings. For these families, thriving means creating clarity and reducing future stress for everyone involved.

These reflections reveal that for many families, thriving is deeply connected to a sense of preparedness. When future plans are in place, caregivers may experience peace of mind and a greater sense of agency. In contrast, uncertainty about what will happen after their death can be a major source of fear, one that threatens not just long-term stability but present-day well-being. Planning for the future, then, is not only a logistical task but a meaningful act of care. Future planning allows both caregivers and people with IDD to imagine a life that remains safe, connected, and thriving over time.

Respite

The need for respite support was raised almost exclusively by family caregivers during the focus groups. Only one comment from a participant with IDD touched lightly on the idea of additional support at home, while family members spoke extensively about their need for relief from caregiving responsibilities. This reflects how deeply respite is tied to family members' ability to sustain caregiving roles and to thrive themselves.

Family members described respite as critical not just for their own well-being, but also for creating a more engaging and fulfilling life for their family member with IDD. One caregiver praised a local program that reframed respite services in a positive, enriching way, saying, “instead of calling it ‘respite’ or ‘care,’ they have...supper club, karaoke club...all of these different clubs that [my daughter] looks forward to” (B.F., Family Caregiver Participant). Access to activities like these was seen as vital to preventing isolation and monotony for their adult children, especially as family caregivers aged. As this same parent explained, without such programs, living at home with aging parents was "not a very exciting lifestyle" for a 38-year-old person with IDD (B.F., Family Caregiver Participant).

> “I need to plan a vacation from my 24/7 job, which is caring for my daughter with a disability…”
>
> —J, Family Caregiver Participant

Other family members discussed the emotional and logistical burdens of caregiving without enough respite. One parent described struggling to find anyone willing to watch their daughter, even briefly, saying: "I'd [tell my other adult children] ‘Y'all, please, you know, just give me an hour...’ [But] ‘Mom, no, we can't do it.’ So...I don't really have the support" (L.B., Family Caregiver Participant). Another parent spoke candidly about the emotional exhaustion that can build over time, stating: “It's not going to get any better. And it just, you know, it just sits here and I'm never gonna get out from under this burden” (B.F., Family Caregiver Participant).

The feeling of burden is consistent with the literature from our environmental scan. Participants in focus groups revealed how burden is lessened when they have adequate access to respite. Family members’ discussion of respite reveal how for them respite is not simply about momentary relief, but fundamental to their ability to maintain energy, and sustain emotional resilience over the long term. Family members’ strong emphasis on the need for respite highlights that thriving is not only about meeting the needs of the person with IDD, but also about sustaining the family members themselves.

Non-Government Support Programs for People with Disabilities

While government support programs were often fraught as described earlier in this report, participants from both groups highlighted the value of non-governmental organizations and community-based support programs in helping individuals with IDD thrive. These included nonprofits such as The Arc, Disability Rights Florida, Special Olympics, and local disability advocacy or service organizations. While the range of services varied, the tone across responses was generally positive, which underscores how these programs fill critical gaps and support social inclusion.

People with IDD described these supports in terms of direct empowerment and advocacy. One participant reflected on his participation in a self-advocacy group, saying “my self-advocate group…they always, they always say to me, ‘do the best no matter--no matter what the circumstances are every day,’” (M.H.G., Participant with IDD). This statement highlighted how non-government groups offered not just programs, but personal agency and advocacy support. For some, organizations also served as entry points to employment and education.

Family members focused on the structural roles that these organizations played, providing services that would otherwise be inaccessible. One caregiver shared, “The Arc Jacksonville actually has... an apartment complex there, and so she has 24-hour services. She has the safety that she needs” (T.W., Family Caregiver Participant). For this participant, a formal service agency with 24-hour supports gave her son what he needs to thrive. Others described how organizations like The Arc or local disability nonprofits were essential for guardianship guidance or information-sharing in their communities.

These supports were especially valuable for families who felt isolated or overwhelmed by the complexities of the disability service system. One parent explained that a guardian advocate helped her understand her legal rights and responsibilities, offering both peace of mind and practical support. In many cases, these non-government programs functioned as bridges, connecting families and people with IDD to community, stability, and belonging.

Ultimately, these organizations were seen as key contributors to thriving. While they could not replace formal government programs, their ability to offer tailored support, advocacy, housing, and community-based services made a meaningful difference in the lives of many participants. Their presence also underscored the importance of a robust and well-resourced nonprofit sector in filling the systemic gaps that government services alone often leave behind.

Online Survey Findings

This section presents the results of the quantitative analysis of the Strive to Thrive online survey with 198 family caregivers of individuals with IDD. The quantitative analysis examined whether thriving for caregivers, their family member with IDD, and families differed by their or their family member with IDD's characteristics. The demographic characteristics of the caregiver and the family members with IDD were presented. Independent samples t-tests and one-way between-subjects ANOVA tests were conducted to examine the differences in the outcome variable (Thriving Score) based on the caregiver and family member with IDD characteristics. Linear regressions were calculated to examine associations between the interval outcome variable and the predictor variables. The bootstrapping method with selection of 870 random subsets from the original dataset was employed to determine the robustness of the model. A standard level of significance $p < 0.05$ was used for all analyses.

Participant Characteristics

Table 4 (caregiver and family member with IDD characteristics) represents the 198 caregivers who were used in final analysis of the thriving survey. The mean age of participants was 62.7 years (SD = 7.76, range = 50-82 years). Majority of the caregivers were female (83.2%), white (86%), 50-64 years old (58.7%), married (63.2%), had educational qualifications of at least a Bachelor's degree (63.1%), were not employed (54.9%), and had 3 or less family members in the household (78.4%). Only 75% of the participants preferred to answer the question about their family annual income, and majority (62.2%) of who answered the question had a family annual income of $61,000 and above. Caregivers were also predominantly not paid for their caregiving (83.8%), and the majority did not care for more than one individual (69.7%). The care recipients had a mean age of 32.8 years (SD = 7.76, range = 50-82 years).

Family members with IDD were majority male (61%), had a "mild" or "moderate" level of ID (59.9%), and most had IDD only (64.9 %) instead of IDD and a physical disability, IDD and mental illness, or IDD and a sensory disability. Most family members with IDD lived in the family household (72.6%), participated in daily activities such as employment, school, day program, or volunteering (57.1%), and did not have any aggressive or destructive behaviors (59.6%).

Table 4. Caregiver and Family Member with IDD Characteristics, Survey

Caregiver Characteristics			
	N	*M*	*SD*
Age	196	62.7 (Range: 50-82 years)	7.76
Age groups	196		
50-64 years		115	58.7
≥65 years		81	41.3
Race	193		
White		166	86.0
Non-white		27	14.0
Gender	196		
Male		23	11.7
Female		163	83.2
Other		10	5.1
Marital Status	190		
Married		120	63.2
Widowed		17	8.9
Divorced/separated		41	21.6
Prefer not to answer		12	6.3
Education	192		
High school or less		20	10.4
Some college/Associate degree		51	26.6
Bachelors degree		60	31.3
Masters degree or higher		61	31.8
Current employment	193		
Yes		87	45.1
No		106	54.9
Number of family members in household	194		
1 to 3		152	78.4
4 and above		42	21.6
Family annual income	191		
$0-$30,000		18	9.4
$31,000-$60,000		36	18.8
$61,000-$90,000		32	16.8
$91,000 and above		57	29.8
Prefer not to answer		48	25.1
Paid for caregiving	198		
Yes		32	16.2
No		166	83.8

Table 4 (Cont'd). Caregiver and Family Member with IDD Characteristics

Caregiver Characteristics (Cont'd)			
	N	*M*	*SD*
Compound caregiving (caring for more than one individual)	198		
Yes		60	30.3
No		138	69.7
Family Member with IDD Characteristics			
	N	*n*	*%*
Age	189	32.8 (Range: 8-78 years)	13.84
Age groups	189		
0-21 years		39	20.6
22-44 years		120	63.5
≥45 years		30	15.9
Gender	195		
Male		119	61.0
Female		66	33.8
Other		10	5.1
Level of ID	191		
Mild		27	14.1
Moderate		87	45.5
Severe		51	26.7
Profound		19	9.9
Unknown		7	3.7
IDD and Related Conditions	194		
IDD only		126	64.9
IDD+Physical disability		20	10.3
IDD+Mental illness		27	13.9
IDD+Sensory disability		21	10.8
Living Arrangement	197		
In the family household		143	72.6
Living on their own		15	7.6
Supportive living/Group Home		21	10.7
Private/public institutional setting		8	4.1
Other		10	5.1
Daily Activities	191		
Stays home during the day		82	42.9
Has activities (employment/school//day program/volunteering) during the day		109	57.1

Table 4 (Cont'd). Caregiver and Family Member with IDD Characteristics

Family Member with IDD Characteristics (Cont'd)	*N*	*n*	*%*
Aggressive/Destructive behaviors of family member with IDD	198		
Yes		80	40.4
No		118	59.6

Participant Self-Report on Thriving

Directed Responses

When given a list of probable items which may have helped the participant or their family member thrive within the past year, participants were most likely to say Healthcare (80.2%), Technology Supports (78.1%), Taking Medication (76.4%), Eating healthy (73.6%) and Participating in leisure activities (73.1%) helped them to thrive. Participants were least likely to find Counseling or therapy (35.7%), Mindfulness activities (39.5%) or Help from friends (42.4%) to help in their thriving.

Table 5. Self-Report of What Helps Families Thrive

Did the following help you and/or your family member to thrive in the past year? *	Yes % (n)	No % (n)
Help from friends	42.4% (73)	57.6% (99)
Help from family	64.4% (112)	35.6% (62)
Help from paid staff (i.e. support workers, teachers, case managers, day program staff)	69.4% (125)	30.6% (55)
Regular exercise	60.3% (105)	39.7% (69)
Eating healthy	73.6% (131)	26.4% (47)
Healthcare (i.e. to go to doctors and other healthcare professionals; taking medication)	80.2% (150)	19.8% (37)
Taking medication	76.4% (133)	23.6% (41)
Participating in leisure activities (actively choosing to do things for yourself)	73.1% (133)	26.9% (49)
Mindfulness activities (e.g. yoga, meditation)	39.5% (49)	60.5% (75)
Religious or spiritual activities (e.g. attending worship services, prayer)	51.1% (69)	48.9% (66)
Counseling or therapy sessions	35.7% (40)	64.3% (72)
Sibling support (brothers & sisters of your family member with IDD)	53.1% (69)	46.9% (61)
Making future plans (e.g. legal, financial, residential plans)	59% (85)	41% (59)
Technology supports (iPad, phone, communication device, etc.)	78.1% (144)	21.9% (32)
Transportation	62.6% (87)	37.4% (52)

**This represents the valid % out of 100, excluding missing values*

Characteristics of Outcome Measure and Other Independent Measures

Table 6 (Characteristics of outcome measure and other independent measures) represents the 198 caregivers who completed the Brief Inventory of Thriving (BIT) Scale within the survey. The mean score of the BIT was 36.08 (SD = 8.3, range = 10-50). Other independent measures were categorized into “Caregiver social supports, satisfaction, and self-efficacy” and “Supports received by people with IDD”.

“Caregiver social supports, satisfaction, and self-efficacy” included 5 measures: Caregiver satisfaction score with a mean of 15.45 (SD = 2.90, range = 5-20), social support score with a mean of 10.64 (SD = 3.86, range = 0-16), social participation score with a mean of 12.00 (SD = 5.31, range = 6-30), caregiver self-efficacy score with a mean of 17 (SD = 3.01, range = 5-24), and the number of reciprocal supports received from person with IDD with a mean number of supports being 1.89 (SD = 1.39, range = 0-7).

“Supports received by people with IDD” included 3 measures: Number of formal services received with a mean number of 2.31 (SD = 1.83 , range = 0-8), number of unmet formal service needs with a mean number of 2.01 (SD = 2.01, range = 0-7), and time spent providing help to a person with IDD with a mean number of 59.67 hours a week (SD = 55.99, range = 0-168).

Table 6. Characteristics of Outcome Measure and Other Independent Measures

Outcome Measure	N	Mean	SD	Range
Brief Inventory of Thriving (BIT) Score	198	36.08	8.30	10-50

Other Independent Measures	N	Mean	SD	Range
Caregiver social supports, satisfaction and self-efficacy				
Caregiver Satisfaction Score	196	15.45	2.90	5-20
Social Support Score	198	10.64	3.86	0-16
Social Participation Score	167	12.00	5.31	6-30
Caregiver Self-Efficacy Score	193	17.00	3.01	5-24
Number of Reciprocal supports received from family member with IDD	198	1.89	1.39	0-7
Supports received by family member with IDD				
Number of formal services received	188	2.31	1.83	0-8
Number of unmet formal service needs	198	2.01	2.01	0-7
Time spent providing help to family member with IDD	189	59.67	55.99	0-168

Differences in Caregiver Thriving by Caregiver and Family Member with IDD Characteristics

Independent samples t-tests and one-way between subjects ANOVA tests were conducted to examine the differences in the outcome variable (Thriving score from the BIT) based on the caregiver characteristics (i.e., age groups, race, current employment status, number of family members in household, caregiver compensation status, compound caregiving, receiving formal services, having unmet formal service needs, gender, marital status, education, and family annual income) (Table III). Independent samples t-tests and one-way between subjects ANOVA tests were also conducted to examine the differences in the outcome variable (Thriving score from the Brief Inventory of Thriving) based on family member with IDD characteristics (i.e., living arrangement, daily activities, aggressive/destructive behaviors, age groups, gender, level of ID, and IDD related conditions) (Table 8).

Independent-samples t-test showed that there was a significant difference in the thriving scores between age groups of caregivers 65 or older (Mean=38.02, SD=6.74) and caregivers 50-64 years old (Mean =34.48, SD=8.89; t(194)=-3.03, $p < 0.01$, such that caregivers 65 years or older had significantly higher thriving scores than caregivers who were between 50-64 years.

There was also a significant difference in the thriving scores between the caregivers who had unmet formal needs (Mean =34.23 SD=7.74) and those who did not have unmet formal service needs (Mean=39.16, SD=8.35; t(196)=4.21 $p < .001$), indicating that caregivers with unmet formal service needs had lower thriving scores than caregivers who did not have unmet formal service needs.

One-way ANOVAs were conducted to examine the caregiver group differences in gender, marital status, education, and family annual income. The groups included gender (male, female, or other), marital status (married, widowed, divorced/separated, prefer not to answer), educational status (high school or less, some college/associate degree, bachelor’s degree, master’s degree or higher), and family annual income ($0-$30,000, $31,000-$60,000, $61,000-$90,000, $91,000 and above).

The results of the ANOVA tests showed that the thriving score differed significantly based on gender, $F(2, 193)= 6.58$, $p < 0.01$. A post hoc Tukey test showed that male caregivers (Mean=41.83, SD=6.74), had significantly higher thriving score than female caregivers (Mean=35.37, SD=8.23), p = 0.001 and caregivers of other gender (Mean=34.50, SD=9.01), p = 0.047.

Table 7. Differences in Thriving Score by Caregiver Characteristics Groups (n=198)

Characteristics	Thriving Score (Brief Inventory of Thriving)	
T-test	M (SD)	t
Age groups		-3.03**
50-64 years	34.48 (8.89)	
≥65 years	38.02 (6.74)	
Race		-1.05
White	35.82 (8.09)	
Non-white	37.63 (9.54)	
Current employment		0.50
Yes	35.89 (8.84)	
No	36.48 (7.83)	
Number of family members in household		0.85
1 to 3	36.32 (8.39)	
4 and above	35.10 (8.13)	
Paid for caregiving		-0.57
T-test	M (SD)	t
Yes	36.84 (7.33)	
No	35.93 (8.49)	
Compound caregiving (caring for more than one individual)		1.04
Yes	35.15 (7.75)	
No	36.48 (8.53)	
Receiving formal services		-1.78
Yes	36.85 (7.86)	
No	34.30 (8.53)	
Have unmet formal service needs		4.21**
Yes	34.23 (7.74)	
No	39.16 (8.35)	
ANOVA	M (SD)	F
Gender		6.58**
Male	41.83 (6.74)	
Female	35.37 (8.23)	
Other	34.50 (9.01)	
Marital Status		1.90
Married	36.81 (8.37)	
Widowed	35.88 (6.97)	
Divorced/separated	33.49 (8.31)	
Prefer not to answer	38.17 (9.22)	
Education		1.17
High school or less	33.80 (9.65)	
Some college/Associate degree	35.37 (7.92)	
Bachelors degree	37.47 (7.82)	
Masters degree or higher	36.00 (8.82)	

Table 7. Differences in Thriving Score by Caregiver Characteristics Groups (Cont'd) (n=198)

ANOVA	M (SD)	F
Family annual income		2.22
$0-$30,000	32.22 (9.32)	
$31,000-$60,000	34.31 (7.59)	
$61,000-$90,000	37.78 (8.91)	
$91,000 and above	36.81 (9.22)	

*Note. Results after bootstrapping, **<0.01, ***<0.001*

Independent-samples t-test were also conducted to compare the thriving scores of family members with IDD groups that differed by living arrangement, daily activities, and aggressive/destructive behaviors. There was a significant difference in the thriving score based on living arrangement, with family members with IDD living outside of the home (Mean=39.06, SD=8.00) having a higher thriving score than those living in the family household (Mean =34.93, SD=8.30; t(196)=-3.20 p <0.01.

There was also a significant difference in thriving score between family members with IDD who did not have aggressive/destructive behaviors (Mean=38.34, SD=7.23) and those who did have aggressive/destructive behaviors (Mean =32.74, SD=8.69; t(196)=-4.93 p < 0.01, such that caregivers who cared for their family members with IDD with no aggressive or destructive behaviors had a higher thriving score compared to the caregivers who cared for family members with IDD with aggressive or destructive behaviors.

Additionally, one-way ANOVAs were also conducted to examine the group differences in age groups, gender, level of ID, and related conditions of family members with IDD. The groups included age groups (0-21 years, 22-44 years, and 45 or older), gender (male, female, or other), level of ID (mild, moderate, severe, profound) and IDD related conditions (IDD only, IDD and physical disability, IDD and mental illness, IDD and sensory disability). The results of the ANOVA tests showed that there was a significant difference in thriving scores based on the age groups of the family members with IDD, F(2,186)=6.90, p < 0.01. A post hoc Tukey test showed that caregivers whose family member with IDD were 45 years and above (Mean=38.93, SD=6.65), had significantly higher thriving score than whose family member with IDD were 0-21 years of age (Mean=31.97, SD=8.93), p = 0.002. Caregivers whose family member with IDD were 22-45 years (Mean=36.43, SD=8.18), also had significantly higher thriving score than whose family member with IDD were 0-21 years of age (Mean=31.97, SD=8.93), p = 0.009.

Table 8. Differences in Thriving Score by Family Member with IDD Characteristics Groups (N=198)

Characteristics	Thriving Score (Brief Inventory of Thriving)	
T-test	M (SD)	t
Living in family household		-3.20**
Yes	34.93 (8.30)	
No	39.06 (8.00)	
Daily Activities		-1.47
Stays home during the day	35.04 (7.29)	
Has activities (employment/school//day program/volunteering) during the day	36.82 (8.99)	
Aggressive/Destructive behaviors of family member with IDD		-4.93**
Yes	32.74 (8.69)	
No	38.34 (7.23)	
ANOVA	M (SD)	F
Age groups		6.90**
0-21 years	31.97 (8.93)	
22-44 years	36.43 (8.18)	
≥45 years	38.93 (6.65)	
Gender		0.51
Male	36.49 (7.94)	
Female	35.44 (8.95)	
Other	34.50 (9.01)	
Level of ID		2.19
Mild	38.15 (7.09)	
Moderate	37.05 (8.23)	
Severe	34.20 (8.44)	
Profound	34.05 (9.99)	
IDD and Related Conditions		1.34
DD only	36.76 (8.18)	
Physical disability	34.15 (8.86)	
Mental illness	33.78 (7.83)	
Sensory disability	35.81 (8.91)	

*Note. Results after bootstrapping, **<0.01*

Linear Regression

Table 9 presents the results of the univariate and multiple linear regression analyses. We first conducted univariate linear regression analyses to examine the association between each predictor variable and the outcome variable, the thriving (BIT) score. Only those predictor variables were included in the multiple linear regression model that showed a p value of 0.20 or less in the simple univariate linear regressions because using a traditional p value level of 0.05 could fail to identify variables of known importance (Bendel & Afifi 1977; Mickey & Greenland 1989). The univariate analyses identified the following variables as significant predictors: [caregivers' age, caregivers' gender, caregivers' marital status, caregivers' family annual income, family member with

IDD's age, family member with IDD's related conditions, family member with IDD's living arrangement, family member with IDD's living arrangement, family member with IDD's level of ID, family member with IDD's daily activities, family member with IDD's aggressive/destructive behaviors, caregiver satisfaction, caregiver social support, caregiver social participation, caregiver self-efficacy, number of reciprocal supports received from family member with IDD, number of formal supports received by family member with IDD, number of unmet formal supports for family member with IDD, and time spent providing help to family member with IDD]. The other caregiver characteristics (i.e., race, education, employment status, caregiver pay, and compound caregiving) and family member with IDD's gender were not found to be statistically significant predictors.

These variables were subsequently entered into a multiple linear regression model to assess their independent associations with the outcome while adjusting for other predictors. A few assumptions of the multiple linear regression were tested. Multicollinearity, i.e., two or more predictors turning out to be highly correlated resulting in model impairment, was tested. First, correlations between predictor variables were investigated for any high coefficients (greater than 0.9). The correlations between predictor variables for all the multiple regression models were less than 0.8. Second, collinearity diagnostics were evaluated. A high variance inflation factor (VIF>10) indicates that the predictor variables have a strong linear relationship with one another. Tolerances are related to VIF as 1/VIF; hence a tolerance below 0.2 is considered problematic (Field, 2013). The VIFs for the multiple linear regression models for the current study were less than 3 and tolerances are high exceeding 0.2. Therefore, it can be safely said that no multicollinearity exists within the data. Next, cases with relatively large standardized residuals were checked to see if there are any cases that could exert undue influence on the models. It is acceptable if 99% of cases have standardized residuals between -3 and +3 or a little below or above these limits respectively. Using the Case wise diagnostics, a list of all cases with values that fell outside this range were generated. All the cases were within ±3 for the linear regression model with the thriving score as outcome variable. And finally, the magnitude of influence a predictor variable has on the predicted value of the outcome variable was calculated using the measure, Cook's distance, was calculated. Cook's distance represents measure of influence on overall fit of a linear regression model, and it captures the impact of an observation from the outlying standardized residuals as well as the leverage, which is the observation's distance from the other observations. A rule of thumb is to identify observations with a Cook's distance of 1.0 or greater (Boussiala, 2020). In the current study, the Cook's distance for the linear regression models ranged from 0.00 to 0.19 indicating that there was no substantial influence by the cases in affecting the estimated regression coefficients.

The multiple linear regression results showed that only caregivers' social support (B=1.06, 95% CI [0.57, 1.68]) and social participation (B=0.60, 95% CI [0.19, 0.98]) contributed significantly to the model which meant that caregivers who had more social support and were involved in social participation had a higher thriving score. The overall model was statistically significant for the thriving score, F(22,81)=10.80, p<0.001, R^2_{adjusted}=0.677, and the model explained 67.7% of the variance for the dependent variable. It is interesting to note that caregiver's gender predicted the thriving score, (B=-3.22, 95% CI [-6.43, 0.15]), however, the p value was 0.059, just below the significance value of 0.05.

Table 9. Summary of the Linear Regression for Thriving Score (N=198)

Variables	Univariate Linear Regression				Multiple Linear Regression			
	B	SE	95% CI	p value	B	SE	95% CI	p value
Caregiver characteristics								
Age	0.25	0.07	[0.12, 0.39]	<0.001	-0.06	0.09	[-0.26, 0.11]	0.519
Race								
White (Ref)								
Non-white	1.81	1.87	[-2.15, 5.35]	0.322	-	-	-	-
Gender								
Male (Ref)								
Female	-3.97	1.52	[-6.92, -0.98]	0.006	-3.22	1.60	[-6.43, 0.16]	0.059
Other	-1.66	2.83	[-7.40, 3.86]	0.556	-5.24	5.20	[-14.47, 6.94]	0.242
Marital Status								
Married (Ref)								
Widowed	-0.21	1.78	[-3.93, 3.22]	0.911	-1.03	2.11	[-5.28, 3.16]	0.618
Divorced/separated	-3.26	1.48	[-6.34, -0.55]	0.033	-0.39	1.48	[-3.32, 2.54]	0.776
Education	0.40	0.43	[-0.48, -1.28]	0.349	-	-	-	-
Current employment								
No (Ref)								
Yes	-0.60	1.22	[-3.03, 1.88]	0.631	-	-	-	-
Number of family members in household	-0.65	0.56	[-1.69, 0.49]	0.251	-	-	-	-
Family annual income	1.47	0.68	[0.21, 2.83]	0.032	-0.86	0.73	[-2.30, 0.65]	0.219
Paid for caregiving								
No (Ref)								
Yes	0.92	1.43	[-2.19, 3.64]	0.491	-	-	-	-
Compound caregiving (caring for more than one individual)								
No (Ref)								
Yes	1.33	1.20	[-0.99, 3.79]	0.281	-	-	-	-
Family member with IDD characteristics								
Age	0.12	0.04	[0.04, 0.21]	0.005	-0.04	0.05	[-0.13, 0.06]	0.420
Gender								
Male								
Female	-0.96	1.32	[-3.51, 1.64]	0.469	-	-	-	-
Other	-1.66	2.92	[-7.54, 4.05]	0.552	-	-	-	-

Table 9 (Cont'd). Summary of the Linear Regression for Thriving Score (N=198)

IDD and Related Conditions								
IDD only (Ref)								
IDD+Physical disability	-2.14	2.05	[-6.32, 1.86]	0.281	-0.12	3.06	[-6.04, 6.53]	0.969
IDD+Mental illness	-2.66	1.64	[-5.76, 0.52]	0.100	-2.40	1.87	[-5.85, 1.53]	0.181
IDD+Sensory disability	-0.30	2.02	[-4.43, 3.34]	0.893	0.04	1.50	[-2.98, 2.94]	0.980
Living in the Family Household								
Yes (Ref)								
No	4.12	1.18	[1.83, 6.38]	0.002	1.47	1.60	[-1.67, 4.38]	0.378
Level of ID	-1.73	0.76	[-3.15, -0.25]	0.019	-0.36	0.70	[-1.69, 0.95]	0.621
Daily Activities								
Stays home during the day (Ref)								
Has activities (employment/school//day program/volunteering) during the day	1.78	1.20	[-0.49, 4.09]	0.147	-1.57	1.29	[-4.17, 1.01]	0.230
Aggressive/Destructive behaviors of family member with IDD								
Yes (Ref)								
No	5.60	1.21	[3.18, 8.08]	<0.001	1.09	1.43	[-1.28, 4.31]	0.455
Caregiver social supports, satisfaction and self-efficacy								
Caregiver Satisfaction	1.24	0.25	[0.71, 1.70]	<0.001	0.13	0.32	[-0.44, 0.84]	0.673
Social Support	1.58	0.11	[1.35, 1.79]	<0.001	1.06	0.28	[0.57, 1.68]	**0.001**
Social Participation	1.10	0.08	[0.95, 1.25]	<0.001	0.60	0.20	[0.19, 0.98]	**0.003**
Caregiver Self-Efficacy	1.29	0.19	[0.95, 1.67]	<0.001	1.29	0.40	[-0.59, 0.97]	0.545
Number of Reciprocal supports received from family member with IDD	0.67	0.38	[-0.08, 1.44]	0.081	-0.05	0.43	[-1.07, 0.64]	0.883
Supports received by family member with IDD								
Number of formal services received	0.85	0.33	[0.16, 1.45]	0.015	-0.18	0.36	[-0.90, 0.51]	0.608
Number of unmet formal service needs	-1.63	0.27	[-2.17, -1.09]	<0.001	-0.11	0.35	[-0.78, 0.63]	0.730
Time spent providing help to family member with IDD	-0.04	0.01	[-0.06, -0.02]	0.002	-0.00	0.02	[-0.03, 0.03]	0.889

Note. Results after bootstrapping

Open-Ended Survey Responses

When asked “Is there anything else you'd like to share about what helps you and/or your family member with IDD thrive?” respondents gave a range of answers. Many used the opportunity to express the challenges they currently face and to share suggestions for services and supports that could better meet their needs. One participant said bluntly, “we are not thriving at all for any second of any day.” Another responded “We are not thriving, we are surviving. I would live [sic] to transition to thriving.” These negative statements were often paired with families’ ideas about what would be helpful in moving them toward thriving. For instance, one mother responded, “would like more recreation opportunities where I don’t have to monitor all of it,” while another simply stated “more social activities, respite care, personal assistant.”

When explaining what supports currently help them thrive or suggesting what supports they would like to have in their life, the most common answers referenced community engagement and leisure opportunities, such as Special Olympics or local organization sponsored activities like “Prom Night” or dance and music classes. Informal community engagement was also cited as an important part of thriving, with one responding “social activities like visiting theme parks, concerts, going out to dinner, etc.” Comments also reflected the lack of these community opportunities for some people with IDD, as one described “My family member needs a quality day program to attend so that the monotony of being home all the time is broken.”

Aside from community engagement, the next most commonly cited support families commented on was paid support services, including the HCBS Waiver, direct support professionals, group homes and independent living arrangements. One parent said, “direct staff at group home, support coordinator and companion are pivotal in my son's ability to thrive,” while another said, “day care through Medicaid Waiver is a lifesaver.” Another explained that their answers have changed due to their family member receiving paid supports that were previously unavailable, saying “…we are truly grateful that our son got off the waitlist and is living a wonderful life.”

> “Community living for her has been a Godsend for me…12 ppl do what I used to have to do alone and it about killed me”
>
> —60-Year-Old Mother

A subset of participants described the importance of affordable housing and particularly various kinds of supported living arrangements. One participant said moving to a community living facility was a “godsend” for her daughter, explaining “12 ppl do what I used to have to do alone and it about killed me.” Another said “[my] daughter lives in a supportive living apartment complex for people with disabilities. This project based complex was a game changer in her life as it helped her to become independent in a safe environment.”

Limitations

While this project employed rigorous qualitative and survey methods to explore what helps aging caregiving families thrive, there were several limitations to consider. These limitations are outlined below to provide transparency and guide the interpretation of findings.

Recruitment Challenges in Spanish-Speaking Communities

Despite extensive outreach efforts and multiple rounds of planning, recruiting Spanish-speaking participants proved extremely difficult. In-person focus groups in Miami and subsequent Zoom sessions each resulted in only one participant, limiting our ability to gather group-level data from Spanish-speaking families. As a result, individual interviews were conducted instead. Although these interviews still provided valuable insights, the small sample size may not fully reflect the broader experiences and cultural perspectives of Florida's Spanish-speaking IDD caregiving community.

Similar challenges made recruiting participants for the Spanish Language survey difficult. While researchers attempted to reach out to service organizations serving Spanish-speaking families for recruitment, ultimately only 5 Spanish Language surveys were included in the final analysis.

Survey Response Bias and Representation

While efforts were made to recruit a diverse and representative sample (including snowball recruitment and outreach to multiple regions and organizations) there is a possibility of response bias. Families who participated may differ in meaningful ways (e.g., having better access to services or stronger networks) from those who did not respond. These differences may limit how broadly the findings can be generalized.

Survey Length and Attrition

During pilot testing, participants reported that the survey was too long. While the research team shortened the survey by removing or replacing several validated scales, there remains a risk that participants may have experienced fatigue or dropped out before completion. This could lead to missing or incomplete data on some survey items, particularly toward the end of the questionnaire.

We used the Qualtrics online survey platform to distribute and manage the survey. One of the advantages of using Qualtrics is that it allows researchers to see how long each participant spent completing the survey. This information helped us understand whether participants were spending enough time to thoughtfully respond to each section, and to identify any patterns in survey fatigue. Participants whose survey was included in the final analysis spent on average 39 minutes completing the survey.

While there were a total of 334 survey responses, responses were excluded because they did not consent to participate (n=6), did not qualify based on age (under 50) or location (outside Florida) (n=17), did not answer any questions past giving consent to participate (n=44), or didn’t complete enough of the survey to be included in the final analysis (n=69). This resulted in a final sample size of 198 versus the original goal of 300 participants.

Focus Group Composition and Sample Size

A total of seven focus groups and four interviews were included in the final analysis. Participants were primarily drawn from those attending the Family Café conference and related networks, which may skew toward individuals who are more engaged with disability advocacy or services.

Use of Cross-Sectional Data

This study relied on cross-sectional survey data, meaning that all data were collected at a single point in time. While this approach provides a valuable snapshot of the current experiences and needs of aging family caregivers, it limits our ability to understand how these experiences evolve over time. Cross-sectional designs cannot capture changes in family dynamics, health, service access, or caregiver stress levels that may occur as individuals with IDD and their caregivers age.

Because the data is captured at a single point of time, it is also not possible to draw conclusions about causality or long-term trends. For example, while we found associations between certain supports and caregiver thriving, we cannot determine whether those supports led to improved outcomes or if more thriving caregivers were simply more likely to access them.

Future longitudinal data collection would allow researchers to follow caregivers and their family members over time, tracking shifts in thriving, service needs, and system navigation.

Discussion

The insights presented below reflect findings from the mixed methods study. This discussion integrates the quantitative survey data with qualitative data from focus groups and individual interviews. By combining these methods, we were able to examine not only statistical patterns in caregiver thriving, but also the lived experiences and perspectives that help explain and contextualize those patterns.

1. Social support and social participation were the strongest predictors of thriving.

The multiple linear regression results from the survey showed that caregivers' social support (B=1.06,95% CI [0.57, 1.68]) and social participation (B=0.60, 95% CI [0.19, 0.98]) contributed significantly to the model, which meant that caregivers who had more social support and were involved in social participation had higher thriving scores. However, in self-report, caregivers were less likely to include "help from friends" or "help from family" as important to their thriving. This apparent disconnect suggests social support may not always be explicitly recognized or prioritized, but plays an important role in their thriving. Future research should explore how caregivers perceive different forms of social support, and whether certain types of social support are more likely to influence thriving.

Previous research has emphasized the critical role of social support (help from family, friends, support groups, etc.) and social participation (caregivers' engagement in community or social activities) in maintaining caregiver well-being. Studies have shown that family caregivers who report having social support have significantly lower stress and burden (Santos et al., 2023), and informal social supports significantly improve quality of life for family caregivers of adults with autism (Samuel et al., 2025) as well as family caregivers of both children and adults with IDD (Boehm & Carter, 2019).

This survey finding aligned perfectly with the focus group and interview theme of Support Networks/Friendships, one of the most common sources of thriving cited in the qualitative portion of this study. Both family caregivers and people with IDD themselves talked about the importance of having a social network and friends in living a good life. One mother explained "neighbors and just my network of friends have all accepted [daughter's name] for who she is" (B.F., Family Caregiver Focus Group).

As described in focus groups, social support was often understood as *interconnected and reciprocal*, not siloed between the person with IDD and their caregiver, but shared across the family system. Social supports designed for the person with IDD (such as self-advocate peer groups or friendships from peers at day support programs) often benefit caregivers indirectly by reducing isolation for their child and providing respite for themselves as caregivers. As one family caregiver described the friendships her daughter has forged through Special Olympics, “when she's accepted, I can relax” (C.A., Family Caregiver Participant). Immediately following this statement, two other family caregivers echoed that what helps them thrive is “when you see them with their friends,” (L.H., Family Caregiver Participant), and “when people know them and accept them for who they are.” (M.S.2, Family Caregiver Participant).

Similarly, when caregivers themselves received social support, they felt more equipped to support their family member with IDD. Focus group participants emphasized the importance of peer support. Caregivers noted that peer support groups and guidance from other families helped them navigate complex service systems and feel less isolated. Two family caregivers who attended a focus group together after having met at their daughter’s shared Special Olympics team explained that they provide social support to one another, saying of their friendship, “it’s ‘ride or die,’ you know?” (C.A., Family Caregiver Participant).

When both members of the caregiving relationship have access to mutual or overlapping social networks (such as inclusive religious groups and supportive communities), social relationships serve dual roles: reinforcing the caregiver’s well-being *and* the inclusion and belonging of the person with IDD. These shared social systems contribute to a broader sense of thriving and resilience for the family as a whole.

2. Female caregivers and caregivers of other genders reported lower thriving than male caregivers.

Survey analysis revealed that thriving scores differed significantly based on gender, with male caregivers having a significantly higher thriving score than female caregivers or caregivers of other gender. This trend suggests that male caregivers, in this sample, may be benefiting from factors that reduce the stressors typically associated with caregiving, including the mental load that often falls more heavily on women (Barigozzi et al., 2025; Dean et al., 2022; Xiong et al., 2018).

When describing the informal support system which helps her son thrive, one female family caregiver explained “the team that I assembled-- and *I* assembled it-- husband was there, but *I assembled it*-- really, is what enabled him to thrive and us to survive.” (L.H., Family Caregiver Participant). Her emphasis on the role she played in building a safe system of support for her son reveals the increased mental load she has taken on as a caregiver, beyond the physical tasks of caregiving. This mental load includes managing appointments, coordinating services, building supportive relationships, and, importantly, keeping track of the emotional and psychological needs of the entire family.

This phenomenon aligns with existing research that shows women often shoulder not only the direct hands-on caregiving tasks but also the responsibility for organizing, planning, and maintaining the overall caregiving framework (Barigozzi et al., 2025; Dean et al., 2022; Xiong et al., 2018). In contrast, male caregivers may benefit from a more defined, often less ambiguous, role within the caregiving process. For example, their contribution is frequently more task-oriented (such as transporting the family member to appointments) rather than managing the 'invisible' tasks such as coordinating care schedules, ensuring the emotional well-being of the family, or navigating disability service systems. As a result, while male caregivers may experience less emotional and cognitive strain, female caregivers are often left to manage the entire caregiving ecosystem, which can lead to higher levels of stress and lower thriving scores.

This finding is also consistent with prior research with family caregivers of adults with IDD, where mothers report their “lives [have] been consumed by their caregiving role.” (Pryce et al., 2017, p.89). In open-ended responses on our survey, mothers took the opportunity to talk about the all-consuming nature of their caregiving, saying “main focus of our life is to care for him [son with IDD]” (61-year-old mother), “it's all I do. I have no life anymore outside of caring for him” (59-year-old mother), and “everything is planned based on our sons needs and not our own. We don't get time away or a break” (60-year-old mother). While open-ended responses from male caregivers and fathers mentioned stress and anxiety, comments did not address the “all consuming” nature of caregiving in the way some of the responses from mothers did.

Another possible cause of lower thriving scores in female caregivers could be women’s tendency to forego their own employment opportunities to more fully devote themselves to caregiving, what research sometimes refers to as “forgone family employment” (Foster et al., 2021). A theme within focus groups was that sometimes family caregivers felt forced to leave the workforce entirely, reduce their hours, or turn down career advancement opportunities. This fell disproportionately on mothers within these groups, which is consistent with prior research (Brown & Clark, 2017; Home, 2004; Leiter et al., 2004; Porterfield, 2002; Scott, 2018). Some of this phenomenon was also revealed in survey responses, in one survey participants open-ended survey response, a mother explained “… I quit my regular job, due to unreliable caregivers in the past, no relationships over 10+ years. I quit going to college, I had no caregiver” (53-year-old mother).

In one focus group, the father of a young woman with intellectual disabilities responded to a mother within the focus group who had just described quitting her job in order to be her son’s full-time caregiver. He said, “you were talking about having to quit your job… my wife had to do that … my wife can't work a regular job because there's nowhere for [our daughter] to go to school” (K.E., Family Caregiver Participant). This exchange underscores how traditional gender norms continue to shape caregiving responsibilities within families. The father’s comment implicitly reinforces the expectation that it is the mother, not the father, who will exit the workforce to provide full-time care. His use of “my wife had to do that” reflects how these decisions are often normalized and expected for women, while men may remain in the labor force even when caregiving demands are high. This aligns with research showing that caregiving responsibilities more frequently disrupt the employment trajectories of women than men (Porterfield, 2002; Leiter et al., 2004). These gendered expectations may contribute to increased stress and lower thriving scores in female caregivers.

3. Caregivers whose family members with IDD lived outside the home experienced higher thriving.

Surveys revealed a significant difference in the thriving score based on living arrangement, with family caregivers whose relative with IDD lived outside of the home (Mean=39.06, SD=8.00) having a higher thriving score than those whose relative with IDD lived in the family household (Mean =34.93, SD=8.30; t(196)=-3.20 p <0.01).

This finding is consistent with previous research. An estimated 71–80% of individuals with IDD in the U.S. live in the family home under a caregiver’s support (Heller et al., 2018). Research shows that caregivers often experience relief and improved well-being when their adult family member with IDD is living outside the home (Mailick Seltzer et al., 2001; Zambrino & Hedderich, 2021). A longitudinal study following families of adults with IDD as they transitioned to residential care found that mothers whose son or daughter moved out reported less worry about their child’s future and greater satisfaction with the amount of contact they had, compared to mothers who continued co-residing (Seltzer et al., 2001). With decreased hands-on caregiving responsibilities, mothers also had improved health due to having more time for their own health needs (Seltzer et al., 2001). Conversely, aging parents who co-resided with their adult child with disabilities were experience steeper increases in depressive symptoms and body mass index (BMI) than parents whose child with disabilities lived away from home (Namkung et al, 2018). While families may feel some initial guilt after residential placement, mothers’ worries significantly decline in the long term and finally drop below the level of the comparison group consisting of mothers who continued to live with their adult child with intellectual disability (Mailick Seltzer et al., 2001).

In focus groups, both people with IDD and their family members consistently expressed that independent living, particularly in terms of housing, was an important part of thriving. One family caregiver in a focus group explained that after various struggles, their son is now thriving in an independent living home, highlighting that he was "living [his] best life" with friends, activities, and autonomy over her daily routine (S.H., Family Caregiver Participant). Another explained that their daughter’s experience in an assisted living community which allows her to live in her own apartment, get part time support from DSPs, and have access to a “clubhouse, and they have activities all day long.”

(C.S., Family Caregiver Participant). As she described this living situation, other caregivers responded with “Wow,” “Oh dang,” and “Oh my God,” expressing their interest in similar living situations for their children.

However, families reported significant barriers to their child living outside of their home. The most common barrier was availability of these types of services and the affordability of housing. One parent explained finding supportive services involved “knowing what to do and what hoops to jump through… good luck and try to figure it out yourself, because nobody knows what’s going on” (K.E., Family Caregiver Participant).

Another key barrier to community living for family members was ensuring their relative’s safety, with focus group and interview participants speaking candidly about the difficulty of ensuring their relative is protected. Some family members expressed concerns about trusting caregivers. One father explained “We're supposed to be empty nesters now. He's supposed to be out on his own. He wants to be on his own. He can't do it, can't drive, can't do manage money… he's always going to be with us, and we love him to death, unless we find him housing that we can trust or we can't trust. Is it safe? Is it not safe? Because he's vulnerable.” (M.M., Family Caregiver). Others reported past experiences with group homes or other independent living situations that did not work for their family member. One mother explained “Moved into a group home, and it is his third one… the first one, he was physically abused…the second group home was a neglect…” (S.H., Family Caregiver Participant). Another explained that her son was in a group home during COVID lockdowns and “he became suicidal,” so he moved back into her home (L.H., Family Caregiver participant).

When people with IDD are able to access independent living situations that are safe and appropriate, family caregivers are likely to have high levels of thriving when they are living outside the home. As one focus group participant succinctly put it, “So when the services work, they *work*.” (C.S., Family Caregiver Participant).

4. Caregivers of adults with IDD had significantly higher thriving than those caring for children/youth (0–21 years).

Caregivers whose family member with IDD were 45 years and above (Mean=38.93, SD=6.65), had significantly higher thriving score than whose family member with IDD were 22-45 years (Mean=36.43, SD=8.18), and also had significantly higher thriving score than whose family member with IDD were 0-21 years of age (Mean=31.97, SD=8.93), p = 0.009. This reveals that as children age, family caregivers’ thriving score increases, especially after the family member with IDD moves from the school-age minor category (age 21) into the adult category (22-45).

The research comparing parenting children vs. adults with IDD has been mixed and inconclusive. Some international studies have shown parents of adults with IDD have higher quality of life and better psychological outcomes than parents of children with IDD (Giné et al., 2015; Pozo & Sarriá, 2015; Scheibner et al., 2024), and at least one US study revealed that older parents of people with DD had significantly fewer negative effects of having a disabled child than younger parents (Ha et al., 2008). However, another U.S. study of parents of both adult children with IDD and minor children with IDD showed no significant correlation between the child's age and overall family QoL (Boehm & Carter, 2019). Another study showed that many aging parents of adult children with IDD have worse health, heightened stress, or declining quality of life in later life, reflecting the cumulative toll of lifelong caregiving (Namkung et al., 2018). Furthermore, Dembo and colleagues (2025) conducted a study with an accelerated longitudinal design to determine the health, mental health, and cognitive functioning outcomes of mothers of children with developmental disabilities beginning in their 20s and extending until their 80s or beyond from two separate studies, namely Midlife in the United States (MIDUS) study (Brim et al., 2020) and Adolescents and Adults with Autism study (Hong et al., 2023; Seltzer et al., 2003). The results of combined analyses of these two studies revealed very similar patterns that accelerated aging in health and cognition began around 65 years for these mothers with patterns suggesting of 'wear and tear' effects due to stress.

Kwong et al. (2025), conjecture that while "there is no conclusive evidence" why family caregivers of adults with IDD sometimes have higher quality of life than family caregivers of children, "one explanation may be that families with older-aged members with intellectual disability have longer years of caregiving experience and thus, they have maintained a higher degree of stability throughout the caregiving journey" (p. 8).

The needs of family caregivers of people with IDD are dynamic and change over the course of the lifespan. Some caregiving challenges lessen or become more manageable with time and experience, even as new concerns (like the caregiver's own aging and future planning) come to the forefront.

5. Behavioral challenges in the person with IDD significantly reduced caregiver thriving.

Family caregivers whose relative with IDD did not have aggressive/destructive behaviors (Mean=38.34, SD=7.23) had higher thriving scores than family caregivers whose relative with IDD did have aggressive/destructive behaviors (Mean =32.74, SD=8.69; $t(196)=-4.93$ $p < 0.01$).

The complexities of managing dual diagnosis of both IDD and mental health issues may be underrepresented in existing literature due to diagnostic overshadowing, a phenomenon where the symptoms of mental illness are misattributed to the underlying developmental disability (Carnaby & Pawlyn, 2008; Kelley et al., 2024; Turygin, 2013). This can result in incomplete or skewed assessments of the extra challenges associated in caregiving for people with IDD who also have challenging behavior. In response to this, we chose to not only ask about the presence of mental illness in family members with IDD, but to specifically inquire about aggressive and destructive behaviors as a way of better assessing the behavioral challenges families face. These behaviors are often a prominent issue for families managing a dual diagnosis, as they can be both a symptom of mental illness and a manifestation of an individual's IDD.

A recent scoping review of qualitative studies of parents of adults with IDD and challenging behaviors revealed that while the parents want to encourage independence in their adult children, "their role of caring for their adult child with an intellectual disability was extended indefinitely due to the persistent and sometimes intensified challenging behaviours exhibited by their adult child with an intellectual disability." (Kwong et al., 2025, p. 5). Family caregivers are often on the receiving end of aggressive behavior, impacting their relationship with the person with IDD and leading to burnout (Griffith & Hastings, 2014; Royston et al., 2023).

In focus groups, one mother described the impact of her son's behavior on their lives together as well as his service delivery. She explained that things shifted during puberty for him, with a diagnosis of intermittent disruptive mood dysregulation disorder. He began seeing a psychiatrist in middle school and spent time finding proper medication to help his mood. She went on to explain "…at age 19, we put him in a group home, which was impossibly hard. But his violence was towards me…. I've been chased with steak knives, I've been choked, I've been smothered, I've been-- he came out one night with a baseball bat behind his back…" She went on to explain that eventually her son moved back home, and they are able to rely on occasional behavior supports through an occasional "respite home" which has a bed prepared for him. She said " he hasn't had [a behavioral outburst] for three years, but should he have an outburst, we have a respite home." This mother's account illustrates the profound toll that aggressive behaviors can take on family caregivers, both emotionally and logistically. Her experience echoes the survey findings and existing literature, highlighting how behavioral challenges can disrupt daily life, determine access to services, and heighten caregiver stress.

It is also important to note that aggressive and challenging behavior in adults with IDD can also have secondary effects which impact families, since people with challenging behaviors are often excluded from formal services like day programs or denied placements in other disability service systems (Smith et al., 2022). This leads to both increased caregiving burden for families by being unable to access formal supports, as well as increased social isolation, since families are unable to access crucial peer supports from other parents receiving similar disability services.

6. Qualitative findings highlighted caregivers' personal strengths as key to thriving.

Focus group participants emphasized a number of personal strengths as important to thriving for both family caregivers and people with IDD. These strengths included maintaining a positive attitude, engaging in hobbies that brought enjoyment and structure, and participating in advocacy and self-advocacy efforts.

Family caregivers spoke about the value of a positive attitude when navigating the challenges of caregiving. One caregiver shared, "you cannot choose what happens to you, but you can choose how you're going to deal with it," (E.M., Family Caregiver Participant). Others talked about the importance of having a sense of humor and "choosing your battles."

While people with IDD were more likely than family caregivers to emphasize hobbies as important to their thriving, family caregivers would often talk about their family member's interests, especially if those interests help the individual form more social network connections. This included interest in attending sporting events, participating in Special Olympics, listening to music, going fishing, and more.

7. Thriving scores were found to be higher among caregivers who did not have unmet service needs

Survey analysis revealed a significant difference in the thriving scores between the caregivers who had unmet formal needs (Mean =34.23 SD=7.74) and those who did not have unmet formal service needs (Mean=39.16, SD=8.35; t(196)=4.21 p <.001), indicating that caregivers with unmet formal service needs had lower thriving scores than caregivers who did not have unmet formal service needs.

This finding was consistent with theme 5 of the focus groups, "Formal Supports and Services." Despite the known benefits of formal supports, families are often forced to act as the primary and sometimes sole care system for their family member with IDD due to a combination of barriers to accessing services, limited availability of resources, and precarity of service systems. Family caregivers frequently report that they are playing a central role in providing care and acting as a de facto provider for their family member when formal support services could help lessen this load. Focus group discussions revealed that many families feel trapped in these roles, knowing that formal services could alleviate some of the pressure, but nonetheless finding it difficult to access needed supports.

Family caregivers in focus groups, as well as survey respondents, reported a sense of relief when they were taken off waitlists or otherwise able to access formal services. As one survey participant explained in her open-ended response, after her daughter qualified for formal support in a community living setting, "12 ppl do what I used to have to do alone and it about killed me" (60-year-old Survey Participant). Families in focus groups expressed similar sentiments, saying that access to formal services requires families to "fight for the services" (J., Family Caregiver Participant).

Focus group participants overwhelmingly described the Medicaid waiver program in particular as essential to thriving. Families who had access to the waiver described it as like getting "Wonka's golden ticket" (T.W., Family Caregiver Participant). Waivers opened the door to vital services such as personal care, community integration, and supported employment. However, many also detailed the emotional and financial toll of long waitlists, unclear eligibility rules, and inconsistent service delivery. Some had waited nearly a decade for services, or had been told they "just didn't qualify" despite high levels of need. One survey participant remarked "After 18 years on a waiting list for the waiver he has finally been approved. However, finding suitable caregivers is going to be challenging. Currently my husband and I are still providing all the care 24/7."

Focus group participants also consistently emphasized the need for accessible and reliable respite services. Many caregivers described experiencing exhaustion, burnout, and a lack of personal time due to the 24/7 demands of caregiving. While not found to be statically significant in thriving, 30.8% of respondents (n=61) in our survey reported an unmet need for respite care services. Research has consistently found that access to respite care significantly reduces caregiver stress and improves overall family functioning (Williamson & Perkins, 2014; Reinhard et al., 2024). Findings from the Environmental Scan for this project also reinforce that respite availability is a key determinant of family resilience and thriving (Marsack-Topolewski, 2023).

Barriers to accessing all types of formal services included long wait lists for services, complicated application processes, lack of availability in their geographic area, and financial constraints. For many families, these barriers mean that they must either provide more care themselves or go without necessary supports altogether, exacerbating stress and contributing to lower levels of thriving.

Recommendations

The integrated findings, grounded in both numerical data and participant voices, inform the following recommendations aimed at improving outcomes for people with IDD and their aging caregivers.

1. Strengthen Social Support and Social Participation Opportunities

Since caregivers who had more social support and were involved in social participation had higher thriving scores, strengthening opportunities for social support and participation are a key intervention tool for these families. This recommendation includes funding and facilitating peer support networks, caregivers' communities of practice, and culturally tailored caregiver affinity groups, supporting caregiver participation in community life, including through transportation, respite services, or flexible programming, and recognizing and investing in informal support structures, such as extended family or faith-based communities.

a. Fund and facilitate peer support networks, caregiver communities of practice, and culturally tailored caregiver affinity groups

Developing and maintaining **peer support networks** or peer navigator programs for family caregivers of people with IDD could help meet the critical need for social support. These programs could be staffed by trained peer-to-peer family caregivers who can assist others in accessing services, understanding options, and building networks. This recommendation is consistent with the literature included in the Environmental Scan for this project, which found that a state-wide family support project for ageing caregivers of adults with IDD led to a reduction in reported barriers to accessing services (Marsack-Topolewski, 2023). Reviews of peer support for families of children with developmental disabilities emphasize that supportive networks can complement formal services and reduce caregiver burden (Chakraborti et al., 2021). Promoting peer networks across the lifespan is crucial, especially as families experience major transitions such as leaving the school system or aging into new service systems. "No Wrong Door" systems and caregiver support groups can also point families to disability service resources and provide hands-on guidance. No wrong door programs involve distributing clear materials in settings such as community centers and religious congregations on relevant topics, as well as connecting caregivers to peers who have practical tips on using those services (Centers for Medicaid and Medicare Services, n.d.).

Peer-led groups for people with IDD may also lead to increased autonomy, independence, and life satisfaction for Floridians with disabilities, all key elements of thriving. These peer led groups can incentivize peer support roles through stipends or formal certification programs that recognize the expertise of lived experience. There is support in the literature for the effectiveness of social support interventions across different types of groups (Hogen et al., 2002). Social and community interventions for people with IDD requires purposeful strategies that identify meaningful participation (Giummarra, 2022). In consideration of the reported barriers to transportation among focus group participants, these peer-led groups should also consider including dedicated funding to cover for transportation for interested participants.

Caregiver communities of practice bring together family members and professionals to share knowledge and resources. These networks enable caregivers to learn from peers navigating similar life-course transitions, mitigating isolation through collaborative problem-solving. Establishing formal caregiver communities of practice can help families of people with IDD collectively address challenges, share local resources, and bolster resilience.

The Administration for Community Living’s National Strategy emphasizes developing culturally competent systems to support individuals with IDD and their families across the (Administration for Community Living, 2022). **Culturally tailored caregiver affinity groups** connect families who share a common cultural or linguistic background, ensuring that support feels personally relevant and accessible. Programs can reduce barriers related to stigma, communication, or mistrust of services by structuring support around shared identities. In practice, culturally tailored affinity groups might include bilingual peer leaders, meetings in community settings, or collaboration with cultural and faith-based organizations. These culturally informed groups can broaden the reach of support and strengthen engagement for historically underserved caregivers (Dodds et al., 2018).

b. Support caregiver participation in community life, including through transportation, respite services, or flexible programming.

Caregivers of adults with IDD often must be the primary drivers for appointments and community outings. National caregiving reports as well as literature regarding HCBS services call for expanding both medical and non-medical transportation options for families (Fox-Grage, 2020; Friedman, 2025). **Transportation support** can include partnering with transit agencies or rideshare programs to provide subsidized, accessible rides, volunteer driver networks, or paratransit vouchers.

Affordable, flexible **respite services** are essential not only for allowing caregivers to leave home safely but also for promoting their overall well-being, reducing stress, and preventing burnout. High-quality respite care gives families time to rest, attend to personal needs, and maintain their own health, all critical to thriving. Research shows that access to respite is associated with improved physical and emotional outcomes for caregivers. To expand access, federal initiatives such as the Lifespan Respite Care Program have been developed to strengthen and coordinate state respite systems (Administration for Community Living, n.d.).

Community services and supports must fit caregivers' schedules and needs with **flexible programming**. Caregiver demands often create time constraints that block access to support resources, which in turn increases their need for support (Choi et al., 2024). To address this, programs can offer non-traditional hours such as evening and weekends, drop-in activities, or mobile/home-based options.

c. Recognize and invest in informal support structures, such as extended family or faith-based communities.

Informal support networks such as extended family and faith-based communities can play an important role in thriving for aging family caregivers. Naturally occurring supports often provide emotional support and encouragement, as well as practical assistance. Research indicates that aging caregivers who report higher levels of informal support experience reduced caregiving burden and greater overall well-being (Marsack & Samuel, 2017). Investing in these informal structures through outreach, training, or partnership, can complement formal services.

2. Provide Gender-Sensitive Support Strategies

Since male caregivers had significantly higher thriving score than female caregivers or caregivers of other genders, it is important to provide gender-sensitive support strategies.

a. Address gender-specific caregiving demands, including emotional labor, time demands, and role expectations.

Female caregivers and caregivers of other genders often assume a disproportionate share of the emotional and mental labor associated with caregiving. This mental load is frequently invisible yet deeply impactful, as shown in both survey responses and focus groups, where mothers described their caregiving as “all-consuming.” This is consistent with prior research indicating that women are more likely to manage the full scope of caregiving (including emotional labor), leading to greater emotional fatigue and lower quality of life (Dean et al., 2022; Xiong et al., 2018).

To address these disparities, support strategies should include education and outreach that normalize shared caregiving responsibilities within families and reduce stigma around help-seeking. Programs should also provide tools that reduce the administrative burden of caregiving, such as service coordination, access to peer navigators, and respite that includes care planning assistance.

b. Offer mental health and well-being supports tailored to the needs of caregivers.

The gender gap in thriving is also linked to differences in psychological strain. Female caregivers are more likely to experience depression, anxiety, and chronic stress due to the ongoing demands of caregiving, often compounded by employment disruption and social isolation (Barigozzi et al., 2025; Pryce et al., 2017). Providing tailored mental health supports, such as caregiver-focused counseling, support groups, and mindfulness-based stress reduction programs, can help address these disparities.

Services should be accessible through multiple formats (e.g., virtual and in-person), offered at flexible times, and integrated into existing caregiving support systems. For example, caregiver support groups can be enhanced with facilitated discussions around gendered experiences, workforce reentry, and identity loss, which many women reported as part of their caregiving experience. Mental health services should also be culturally and linguistically inclusive, recognizing that stress may be compounded for caregivers from marginalized communities.

3. Develop Long-Term Planning and Residential Transition Supports

Knowing that family caregivers whose relative with IDD lives outside the home report significantly higher thriving scores, a special focus on long-term planning and residential transition supports is critical. For many families, the absence of future planning leads to crisis-based decisions. Supporting caregivers through proactive, informed transition planning promotes long-term stability and thriving for the whole family.

a. Educate families about residential options and support early, proactive planning for out-of-home placements when appropriate.

Research consistently finds that proactive residential planning is associated with reduced caregiver stress and better long-term outcomes for people with IDD (Heller & Caldwell, 2006). Early conversations about residential options, including supported living, host homes, or group homes, can help caregivers develop realistic, person-centered goals. Educational initiatives, webinars, and planning toolkits can equip families with the information they need to explore these options without stigma or guilt. These efforts are especially important for aging caregivers, who may worry about what will happen when they are no longer able to provide care themselves.

b. Provide assistance with decision-making related to independent living, including guardianship, supported decision-making, and housing navigation.

Navigating the complex systems involved in residential transition requires sustained support. Family caregivers often need guidance on critical decision points, such as whether to pursue guardianship, adopt a supported decision-making model, or identify housing and care arrangements that align with their family member's values and needs. Trained navigators or peer mentors with lived experience can be invaluable in helping families understand these options and access the necessary supports. Programs like *The Future Is Now* have demonstrated the effectiveness of family-centered planning interventions that include both legal and housing components (Factor et al., 2010). Embedding these supports into service systems ensures that families are not left to navigate residential transitions alone.

c. Increase availability of safe, supported living environments for adults with IDD.

Even when families plan proactively, they often encounter a shortage of housing or supported living options. Nationally, there is a documented gap between the demand for supported residential settings and the supply of affordable, high-quality placements (Larson et al., 2012). To address this, states should invest in developing a range of supported living models, including shared living, supervised apartments, cooperative housing, and intentional communities (Center on Community Living, University of Minnesota, 2024). Funding should prioritize individualized and person-centered supports over congregate settings.

4. Target Supports Based on Life Stage of Person with IDD

Knowing that family caregivers' thriving often increases as their relative with IDD ages, it is important to tailor supports for families based on the life stage of the individual with IDD. Early stages of the caregiving journey are often marked by heightened uncertainty, steep learning curves, and increased demands on family time, energy, and resources. By contrast, later stages may involve more stability, established routines, or access to long-term services, at least as long as families are able to provide care. A life-course approach to caregiver support acknowledges that families face different challenges at different developmental stages. Timely, targeted interventions can help promote thriving.

a. Offer intensive, proactive support to families in early stages (e.g., during diagnosis, school entry, and transition to adulthood).

Families often report that the early years, especially immediately post-diagnosis and during school entry, are among the most emotionally and logistically challenging. These stages are marked by steep learning curves, extensive paperwork, and the need to quickly navigate complex service systems (Bailey et al., 2005). Similarly, the transition from school-based services to adult service systems is often described by families as a cliff, due to the sudden drop in supports and structured services (Laxman et al., 2019). Providing intensive, proactive supports during these early and transitional phases can help reduce stress and improve long-term outcomes.

b. Design life-course–oriented caregiver supports, recognizing changing demands at different developmental stages.

The needs of caregivers evolve over time, as do the developmental needs of the individual with IDD. A family supporting a child in early intervention services faces different demands than one navigating adult employment supports or end-of-life care. Life-course oriented programming should anticipate these shifts and provide stage-specific tools, peer connections, and planning resources. Programs like Charting the LifeCourse (CtLC) offer a nationally recognized framework for supporting families and individuals with IDD across the lifespan (University of Missouri Kansas City, n.d.).

c. Support transition planning services that reduce burden on families during key educational and service system changes.

Fragmented services and changing eligibility rules can make major transitions particularly overwhelming for family caregivers. Families report administrative burdens and fear of the unknown during these times. Formal transition planning services can ease this burden. Programs should focus not only on the individual with IDD but also on the needs of the caregiver, offering resources such as legal guidance, mental health support, and respite during periods of transition. Investing in this kind of targeted support infrastructure has the potential to improve thriving across the lifespan.

5. Support Caregivers Managing Challenging Behaviors

Knowing family caregivers whose relative with IDD have aggressive/destructive behaviors are more likely to have lower thriving scores, programs can be designed with a special focus on family caregivers who are managing challenging behaviors with their relative.

a. Provide caregivers with resources and training in crisis prevention and de-escalation techniques

Family caregivers often report feeling unprepared to handle behavioral escalations, especially when their relative with IDD exhibits aggression or self-injury. Community-based providers, advocacy organizations, and disability support agencies can help equip families with the tools they need to prevent and de-escalate crises. These organizations can offer accessible workshops, peer-led training, or online resources that teach practical, evidence-based strategies

b. Expand Crisis Management and Stabilization Services for Families

Family caregivers of adults with IDD who display aggressive or destructive behaviors often lack timely, appropriate crisis support. This can lead to lower thriving, including emotional exhaustion and increased safety concerns for both their relative and themselves. To promote thriving, states should invest in IDD-specific crisis response systems that are trauma-informed. A brief from the Center for Medicare and Medicaid Services (CMS) emphasize that states should have a “behavioral health crisis continuum” which include crisis hotlines, mobile crisis teams, and short-term crisis receiving/stabilization facilities (CMS, 2021).

c. Involve caregivers in behavioral interventions to improve thriving

Caregivers of people with IDD who exhibit aggressive behaviors face evolving challenges across the lifespan. Research shows that interventions targeting aggressive challenging behavior in people with IDD are more effective when they include training for family caregivers (Royston et al., 2023; Prior et al., 2023). Including caregivers in personalized behavior plans and providing ongoing coaching improves outcomes for both the person with IDD and their family (Prior et al., 2023).

Caregivers benefit from training that teaches evidence-based behavior management strategies (Sun, 2022). Behavioral skills training (BST) is a broad model of instruction, modeling, rehearsal, and feedback for families of adults with intellectual disabilities who exhibit challenging behaviors (Sun, 2022). BST has generally shown improvements for both caregivers and the individuals with IDDs. Programs should incorporate BST into their programs, so caregivers are equipped before challenging behaviors escalate.

6. Leverage and Cultivate Personal Strengths and Resilience

Qualitative findings from focus groups and interviews highlighted caregivers’ inner resources as key to thriving. Many family caregivers described how cultivating a positive mindset, pursuing personal interests, and reframing their caregiving role helped them thrive. These personal strengths, though often unacknowledged by formal systems, can be supported and strengthened through intentional programming.

a. Offer resilience-building interventions, such as mindfulness, acceptance and commitment therapy (ACT), or strengths-based coaching.

Evidence-based mental health interventions such as mindfulness-based stress reduction, acceptance and commitment therapy (ACT), and strengths-based coaching have been shown to improve caregiver coping and reduce anxiety, particularly among those caring for individuals with intellectual and developmental disabilities (Singh et al., 2016). These approaches help caregivers develop emotional regulation strategies, practice self-compassion, and identify values that guide their caregiving. Resilience-building interventions may be offered through group workshops, online modules, or individualized coaching.

b. Encourage self-reflection and empowerment programs to build a sense of control and purpose among caregivers.

Programs that support self-reflection and empowerment help caregivers reframe their role not just as a series of responsibilities, but as part of their identity. Focus group participants shared how taking ownership of their family member's care, such as organizing support systems, engaging in advocacy, or simply "choosing your battles," provided a sense of control and accomplishment. As an example, the *Caregiver ECHO* project delivered a virtual, peer-supported behavior-management curriculum to caregivers of children with neurodevelopmental disorders, which significantly improved caregivers' self-efficacy (confidence) and feelings of empowerment after the program (Nevill et al, 2025). Similar interventions for families of adults with intellectual disabilities, such as the *Family Support Navigator* intervention, boast lower stress, depression, and caregiving burden and higher health/family quality-of-life for program participants after participating in the peer-support program (Milberger et al., 2022).

c. Acknowledge and validate the emotional and identity work involved in long-term caregiving.

Caregivers often engage in deep emotional and identity work. This internal labor is rarely acknowledged in formal support systems. Creating space to validate this emotional work can reduce isolation and affirm caregivers' lived experiences. As one caregiver shared during the focus group, "you cannot choose what happens to you, but you can choose how you're going to deal with it" (E.M., Family Caregiver Participant). This kind of reflective wisdom emerges from years of navigating uncertainty and balancing the needs of others with the challenges of caregiving. Programs that center caregivers' voices and experiences help foster belonging and resilience within caregiving communities.

7. Expand and Ensure Access to Formal Supports

Based on the finding that unmet service needs are strongly associated with lower caregiver thriving, it is important to expand and ensure families' access to formal supports. This should include streamlining and simplifying access to formal services, prioritizing equitable service delivery, and developing navigation assistance programs to help families access services throughout the life course of the individual with IDD.

a. Streamline and Simplify Access to Formal Services

One of the most pressing issues faced by families is the complexity and fragmentation of the service delivery system. Simplifying access to formal services such as respite care, behavioral supports, and in-home assistance would help alleviate the challenges caregivers face. Many families report waiting months or even years to secure services due to red tape, scarcity of services, or a lack of clarity about available options. Streamlining the application process, for instance by offering one-stop portals for service coordination, would significantly ease the strain on caregivers. Providing clear, accessible information about service eligibility and coverage to families is a key priority.

In recognition of the critical importance of Medicaid HCBS waivers reported by family caregivers in focus group, an important recommendation is to expand efforts and advocacy to improve access, transparency, and navigation within Florida’s Medicaid HCBS system. Participants described the application process as a “nightmare,” and emphasized the need for clear information and individualized support. The Council could support the development of partnerships with community organizations to help families understand eligibility, complete paperwork, and maintain services over time.

Recent analyses underscore the importance of transparency and targeted funding in HCBS waiver programs. A 2023 KFF report highlighted that over 692,000 individuals were on Medicaid HCBS waiting lists, with the majority being people with intellectual or developmental disabilities. The report emphasized that waiting lists often reflect state decisions regarding service provision and resource allocation, and that increased transparency in reporting can aid in addressing these disparities (Burns et al., 2023).

b. Prioritize Equitable Service Delivery for Caregivers of Individuals with Complex Behavioral Needs

Families of individuals with complex behavioral needs face additional challenges, particularly when accessing formal services. Behavioral support services are often in high demand, but many families encounter long waiting lists or inadequate coverage for behavioral therapies. It is essential that service systems prioritize equitable service delivery for these families, ensuring that those with complex needs are not left behind. Targeted funding for behavior support services, as well as training for caregivers in managing challenging behaviors, would help families feel more supported and confident in their caregiving role.

Equity must also be a key focus when addressing disparities in service provision. For instance, families in rural or underserved areas may face even more significant barriers to accessing services due to a lack of local providers or transportation options, as our focus group participants often highlighted. Prioritizing service equity and targeting funding to high-need areas would ensure that caregivers, regardless of geographic location, have access to the supports they need to care for their family members.

c. Develop Navigation Assistance Programs

Developing navigation assistance programs to support families in accessing services across the entire life course of individuals with IDD will help these families to thrive. Many families encounter significant gaps in support, especially as their relatives with IDD transition out of the school system into adulthood, as well as transitioning into aging service systems. During these transitions, caregivers often struggle to find appropriate services, such as housing options, employment support, or community-based care. By establishing dedicated, long-term service coordinators or navigators who can assist families at every stage, these transitions can be smoother and less stressful.

8. Policy and Program Implications

The Strive to Thrive project defines thriving as a state of positive functioning across multiple domains according to the model by Su et. al (2014) which includes well-being, autonomy, relationships, and purpose. Supporting caregiver thriving requires not only improving access to services but also reshaping how caregiving is understood and embedded in disability service systems. The following policy and program recommendations are grounded in the thriving framework and informed by the lived experiences of caregivers who participated in this study.

a. Integrate caregiver thriving metrics into disability service evaluations.

Current disability service evaluations typically focus on compliance, health outcomes, or service utilization. However, these metrics rarely capture how well caregivers and families are thriving. Integrating thriving measures, such as those aligned with Su et al.’s (2014) domains of subjective well-being, engagement, and optimism, into evaluations would offer a more complete picture of system effectiveness. For example, routine assessments of caregiver emotional health, satisfaction, social connectedness, and perceived control could help agencies track caregiver well-being alongside outcomes for people with IDD.

b. Embed caregiver support in Medicaid waivers and long-term services and supports (LTSS) planning.

Caregiver thriving depends on access to formal services, but also on family caregivers feeling recognized and supported in their role. Embedding caregiver supports into Medicaid Home and Community-Based Services (HCBS) waivers and LTSS planning can enhance caregivers' thriving under Su et al's (2014) model in the subdomains of mastery and accomplishment (through skill-building), and autonomy and control (through flexible supports) (2014). States could include caregiver-specific services like mental health counseling, peer navigation, future planning support, and training in behavior management directly within HCBS waiver language.

c. Fund mixed methods research that continues to center caregiver voices and diversity.

Funding participatory, mixed-methods research that centers diverse caregiver voices, including those from racially, linguistically, and culturally diverse backgrounds, ensures that supports reflect the full range of caregiving realities. Thriving is not a one-size-fits-all concept. By investing in community-driven research and including caregivers as co-researchers and advisors, states can create more equitable, responsive systems that support families in all their complexity.

d. Recognize caregivers as co-actors in service systems and elevate their roles in decision-making.

Family caregivers are not just passive recipients of services, they are key partners in the planning and delivery of supports. Elevating caregivers as decision-makers can strengthen the responsiveness and sustainability of service systems. Caregivers should be compensated for their time and expertise, and systems should invest in leadership development programs that foster caregiver engagement. This shift recognizes caregiving as a source of community knowledge and innovation and advances the goal of systemic thriving for families impacted by IDD.

The Aging Families Taskforce of the Florida Council on Developmental Disabilities exemplifies this approach by formally including caregivers in strategic planning and elevating their perspectives in statewide disability initiatives. Through efforts like the *Strive to Thrive* project, the Taskforce is helping to embed caregiver voices directly into Florida's long-term planning and policy development.

Conclusion

This multi-phase research project helps us to understand what enables aging families of people with IDD in Florida to thrive. The qualitative and quantitative findings reveal that families can be empowered to thrive through strong social connections, accessible services, and targeted supports. Factors which led to higher thriving scores among survey participants included caring for adults instead of children, having their family member with IDD live outside their home, and having higher levels of social support, social participation, and caregiver satisfaction. Focus group findings corresponded with these survey findings and enriched the data with personal stories and additional components of thriving families find important, especially the value of personal strengths as part of thriving.

Combined findings from the survey and focus groups revealed several important strategies to enhance thriving in aging families who support individuals with IDD. Key recommendations point to the need for expanding and improving access to formal support systems, while also strengthening opportunities for social support and community participation. The data emphasize the importance of tailoring interventions specifically for female caregivers and addressing the need for long-term planning, including residential transitions. Additional support is needed for caregivers of young children and those managing challenging behaviors. Promoting family resilience by building on personal strengths emerged as another vital theme, along with the need for greater investment in family support services and better integration of aging and disability systems of care.

Moving forward, these insights should guide policy, programming, and research efforts across Florida. The challenges that aging caregiving families face are significant, but findings reveal they can be mitigated. This report underscores that families can and should move on the continuum from surviving to thriving, when equipped with the right supports, resources, and opportunities for connection.

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Appendices

Appendix A. Codebook for Focus Group Analysis

CODE GROUP	CODES	DESCRIPTION
Informal Supports for Thriving	Support Networks/Friendships	Groups and individuals that provide emotional, practical, and social support to people with intellectual and developmental disabilities (IDD) and their families. Include references to friends, community organizations, and other support groups. Exclude references to family members.
	Emotional Support	Emotional support for both people with IDD and family members. Include peer group support, as well as emotional support within families.
	Instrumental Supports	References to practical assistance, such as help with daily tasks, hygiene, housekeeping, transportation, and financial management. Exclude references to transportation that are not transportation directly provided by a caregiver.
	Reciprocal Supports	Mutual exchange of support between individuals with IDD and their family member. Includes the ways in which individuals with IDD and family members contribute to and receive support from their family relationships.
	Faith & Spirituality	Role of religious and spiritual practices in the lives of individuals with IDD and their families. Includes participation in religious services, prayer, spiritual guidance, and the sense of community provided by religious groups.

Personal Strengths/Resources	Positive Attitude	References to having a positive attitude, positive thinking, or "looking on the bright side." Include statements about resilience and having a sense of humor.
	Hobbies	Benefits of hobby and leisure activities including sports, arts, and other recreational activities that contribute to well-being and quality of life. Include physical health and exercise under the "hobby" code.
	Advocacy	Family members' role in providing advocacy for the family member with IDD. Include statements about the family member teaching the person with IDD about self-direction or self-advocacy. Exclude medical or legal decision-making.
	Self-Advocacy	Participants' expressions of speaking up for themselves, making choices, or being involved in decisions that affect their lives. This includes both formal self-advocacy activities (like being part of advocacy groups or attending trainings) and informal acts (like asserting preferences or asking for support).
Decision Making Supports	Supported Decision Making	Tools, resources, and assistance for people under guardianship that empower them to participate in decision-making. Inclusive of both informal references to decision-making support, as well as references to the formal legal designation of Supported Decision Making.

	Financial Support/Financial Decision Making	Guardian's role in financially assisting individuals with IDD. Include out-of-pocket expenses, management of government benefits (including representative payee), and other financial support. Also include support in decision-making regarding finances.
	Medical Care/Medical Emergencies	Family Member's role in the healthcare needs and medical emergencies of individuals with IDD. Includes access to medical services, support at healthcare provider appointments, and emergency response plans.
	Safety/Protection	Concerns related to the physical, emotional, and social safety of people with IDD, often expressed by family caregivers. Includes fears about vulnerability to abuse, neglect, exploitation, or harm, especially in unfamiliar environments or when interacting with unfamiliar people or systems. Also encompasses efforts by families to protect and advocate for their relatives' safety across settings.
Supports for Independent Living	Autonomy and Self-Determination	Expressions of personal choice, independence, or control over one's own life and decisions. Include participants with IDD's statements about making their own choices, setting goals, or advocating for themselves. Include family caregiver statements about supporting independence, respecting their choices, or navigating the balance between providing care and fostering self-direction.

	Employment for People with IDD	Opportunities and challenges related to finding and maintaining employment for individuals with IDD. Include references to job coaching, challenges obtaining employment, as well as the benefits of employment unrelated to paychecks. Exclude specific references to Vocational Rehabilitation.
	Employment Limitations for Family Members	Limitations on the ability of family members' ability to maintain full-time employment, advance in their careers, or accept promotions due to caregiving responsibilities. Includes cutting back hours, leaving the workforce, or declining opportunities in order to provide supervision, attend appointments, or offer transportation for the person with IDD.
	Activities of Daily Living	Family member's role in supporting people with IDD with essential daily tasks, such as bathing, dressing, eating, and personal hygiene. It includes the support provided to help them perform these activities.
	Independent Living Aspirations & Independent Living Communities	Independent Living Aspirations: Statements of hope, desire, or plans by individuals with IDD to live on their own in the future. Include family caregivers' hope their family member with IDD will live independently. Include aspirations for greater independence, mentions of moving out of a family home or current living situation, and personal goals related to having one’s own space. Independent Living Communities: References to residential communities designed for individuals with IDD who wish to live independently. Includes

		the services, support systems, and community aspects that facilitate independent living.
	Housing Affordability	Financial aspects of securing housing for individuals with IDD. Include the availability of affordable housing options, financial assistance programs, accessibility, and the challenges of finding suitable housing.
Formal Supports/Services	Government programs/supports	Governmental support programs available to individuals with IDD, such as SSI (Supplemental Security Income), Vocational Rehabilitation, CDC+, and Medicaid Home and Community-Based Services Waiver. Include references to the benefits, challenges, eligibility, and application processes of these programs.
	In-Home Caregiving	Care and support provided to individuals with IDD within their own homes by professional caregivers. Include references to funding for services, identification and screening of caregivers, and the type and quality of assistance offered.
	Experience of Precarity with Formal Systems	Precarity captures participants' experiences of instability, uncertainty, and vulnerability related to their services, supports, and futures. This includes fear of losing access to programs like day services, SSI, Medicaid, or waiver supports.

	Transition From High School to Adult Service Systems	Transition process for individuals with IDD from high school to adult service systems. Include transition planning, support services, and the challenges of moving from an educational to an adult care environment.
	Navigating Systems	Ability of individuals with IDD and their families to understand and access various service systems, such as healthcare, education, and social services. Include challenges, barriers, and strategies for effectively navigating these systems.
	Disparities in Services Based on Counties in Florida	Variation in services and resources available to individuals with IDD across different counties in Florida. Includes the accessibility, quality, and types of services provided regionally.
	Transportation	Transportation needs and solutions for individuals with IDD. Include access to public transit, paratransit, and the challenges of mobility and travel.
	Future Planning	Long-term planning for individuals with IDD. It includes financial planning (Special Needs Trusts, ABLE accounts), legal arrangements, transferring guardianship, and the development of strategies to ensure a secure future for family members with IDD.
	Respite	Temporary relief from caregiving responsibilities through formal services (e.g., agency-provided in-home care, day programs, or overnight stays) or informal support (e.g., help from friends, family, or community members). Includes discussions of

		availability, quality of respite options, as well as the impact of respite on caregiver well-being.
	Non-Government Support Programs for PWD	Non-governmental support programs available to individuals with IDD, including Special Olympics, Goodwill, The Arc, or other non-profit support for people with disabilities and their families. Exclude references to governmental programs such as SSI or public schools.

Appendix B. Focus Group Guide: Family Caregivers (English)

Moderator: (Moderator introduce self and give your relation to disability (e.g., Family member, researcher, advocate, etc.)

"Thank you for coming today. We are exploring what helps families of people with intellectual and developmental disabilities (IDD) thrive. We will summarize your responses and use them to better understand the experiences of thriving for families in Florida.

Thriving is defined as “the state of positive functioning at its fullest range- mentally, physically, and socially” (Su et al., 2014). We want to learn about what helps families move beyond surviving, to truly have a fulfilling life and thriving in their communities.

We've brought you together so that we can learn from each other. We are specifically looking at three big questions:

1. First, what helps people with IDD, who are living with their family, thrive?
2. Second, what helps family members of people with IDD thrive?
3. Third, what helps family members support their family member with IDD to thrive?

This is an open discussion. Please feel free to share any experiences or stories you have related to your family’s experiences with thriving throughout our discussion today. We want to know what you are experiencing, so we can learn from you.

We are recording this session so that we can study what you have said, but your names and identifying information go no farther than this group. Anything you say here will be held in strict confidence; we won't be telling people outside this room who said what.

Although we ask all of you in the group to respect everyone’s privacy and confidentiality, and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other participants in the group may accidentally disclose what was said so we cannot guarantee your privacy and confidentiality.

When you have something to say, please repeat your first name each time. When we are listening to the recording again, we will not be able to see who is speaking, and we'll need to be able to relate comments you made at different times. We will use the recording to transcribe the focus groups, though we will not transcribe any names or personal identifying information conveyed. Then, we will destroy the recording so the names or personal identifying information cannot be connected to the data collected.

If it is OK with you, we will turn on the recorder and start now.

This focus group is being conducted for the Strive to Thrive Project on _______[DATE]
by ______(MODERATOR(s)).
START TIME - _____________.

Let's begin with introductions.

1.Please tell us your first name only and what comes to mind when you hear the term "thriving"?

2.What do YOU do to help your family member with IDD to thrive?

3.Besides the help you provide, what ELSE helps your family member with IDD thrive?
Mentally? Physically? Socially?

4.We talked about what helps your family member thrive, now we want to know: What helps YOU thrive as the family member?

- Reflecting on your own well-being, what practices or resources do YOU rely on to thrive mentally, physically, and socially?

5.What ELSE could help you and your family member with IDD thrive?
Mentally? Physically? Socially? Resources (e.g., financially)? Health-care related? Spiritually?

6.How could policies and programs in Florida help your family thrive more now and in the future?

- How could future planning programs help you and your family thrive? (i.e. planning for when you as a family member are no longer able to provide care. This could include financial and legal planning, guardianship transitions, establishing trusts, living arrangements, and support networks.)

7.Is there anything that we may have left out? Anything else you would like to add?

8.Now, we want to learn a bit about your perspective on navigating the state guardianship system. What has been your family's experience with….

- Guardianship or guardian advocacy?
  - Have you done it? What is your understanding of it? What is your experience setting it up and utilizing it?
- Supported decision-making?
  - Have you done it? What is your understanding of it? What is your experience setting it up and utilizing it?
- Other alternatives to guardianship such as: Health care surrogate/proxy; Power of attorney; Representative payee?
  - Have you done it? What is your understanding of it? What is your experience setting it up and utilizing it?

9.Why did you decide to seek guardianship or not?

10.How satisfied are you with the Florida guardianship system?

  - What do you like or not like about it?
  - How could it be improved?

Thank you all for sharing your thoughts and ideas with us today! Again, we will not share any of your names and we will keep the information you shared private and confidential. As a reminder, we ask that each of you do not share the information you heard today or the names of people who shared today. Thank you again!

Appendix C. Focus Group Guide: Family Caregivers (Spanish)

Moderador: (El moderador se presenta y le indica a cada persona su relación con la discapacidad (por ejemplo, miembro de la familia, investigador, defensor, etc.)

"Gracias por venir el día de hoy. Estamos estudiando qué puede ayudar a las familias de personas con discapacidades intelectuales y de desarrollo (DID) para que logren prosperar. Resumiremos sus respuestas para luego usarlas a fin de comprender mejor las experiencias sobre cómo prosperar que tienen las familias en Florida.

Prosperar se define como el “estado de funcionamiento positivo en su mayor amplitud – mentalmente, físicamente y socialmente” (Su et al., 2014). Queremos saber qué puede ayudar a las familias a avanzar, para no limitarse a sobrevivir, sino que lleguen a tener una vida plena y satisfactoria y puedan prosperar en sus comunidades.

Les hemos reunido para que podamos aprender los unos de los otros. Específicamente, queremos centrarnos en estas tres grandes preguntas:

1. Primera, ¿qué puede ayudar a las personas con DID, que viven con su familia, para que logren prosperar?
2. Segunda, ¿qué puede ayudar a los miembros de la familia de las personas con DID para que logren prosperar?
3. Tercera, ¿qué puede ayudar a los miembros de la familia para que apoyen al miembro de su familia con DID para que logre prosperar?

Esta es una discusión abierta. Por favor, en nuestra sesión de hoy, sienta que tiene la libertad de compartir cualquier experiencia o historia sobre prosperidad que desee. Queremos saber lo que ustedes experimentan, para que podamos aprender de ustedes.

Estamos grabando esta sesión a fin de poder estudiar lo que ustedes digan, pero ni sus nombres ni la información que les identifica se sabrán fuera de este grupo. Todo lo que digan se mantendrá en la más absoluta confidencialidad; nadie fuera de esta sala sabrá quién dijo qué.

Aunque le pedimos a todos los participantes del grupo que respeten la privacidad y la confidencialidad de los demás, y que no identifiquen a nadie del grupo ni repitan lo que se diga en la sesión, por favor recuerde que otros participantes pueden, por accidente, revelar lo que se diga; por lo tanto, no podemos garantizar su privacidad y confidencialidad.

Cuando quiera decir algo, por favor repita su primer nombre cada vez que vaya a hablar. Cuando estemos escuchando la grabación, no podremos ver quién habla, y necesitamos poder relacionar los distintos comentarios que usted haga a lo largo de la sesión. Usaremos la grabación para transcribir las sesiones de los focus groups, aunque no se transcribirá ningún nombre ni la información que nos revelen y les pueda identificar. Luego, se destruirá la grabación, de manera que ningún nombre o información identificable se pueda relacionar con los datos recabados.

Si le parece que todo esto está OK, prenderemos la grabadora para comenzar ahora.

Este focus group se lleva a cabo para el Proyecto *Strive to Thrive* (los esfuerzos por prosperar) el día _______[FECHA] y está dirigido por _________(MODERADOR(es)).
HORA DE INICIO - _____________.
Comencemos con las presentaciones.
1. Por favor, indique solo su primer nombre y lo primero que piensa cuando escucha la palabra “prosperar”.

2.¿Qué hace USTED a fin de ayudar al miembro de su familia con DID para que logre prosperar?

3. Además de la ayuda que usted le brinda, ¿qué OTRA COSA puede ayudar al miembro de su familia con DID para que logre prosperar?
¿Mentalmente? ¿Físicamente? ¿Socialmente?

4. Ya hablamos sobre lo que ayuda al miembro de su familia para que logre prosperar, ahora queremos saber: ¿Qué le ayuda a USTED para que logre prosperar como miembro de la familia?

- Si reflexiona sobre su bienestar, ¿en qué prácticas o recursos se basa USTED para lograr prosperidad mentalmente, físicamente y socialmente?

5. ¿Qué OTRA COSA puede ayudarle a usted y al miembro de su familia con DID para que logren prosperar?
¿Mentalmente? ¿Físicamente? ¿Socialmente? ¿Recursos (por ejemplo, financieramente)? ¿En relación con los cuidados de salud? ¿Espiritualmente?

6. Las políticas y programas de Florida, ¿cómo pueden ayudar a su familia para que logren prosperar más, tanto ahora como en el futuro?

- Los programas que se planifiquen para el futuro, ¿cómo podrían ayudarle a usted y a su familia para que logren prosperar? (por ejemplo, planificar para cuando usted, como miembro de la familia, ya no pueda brindar cuidados. Esto puede incluir planificación financiera y legal, transición entre tutores, establecimiento de fideicomisos, condiciones de vida y redes de apoyo).

7. ¿Le parece que hay algo que no se incluyó? ¿Desea agregar algo más?

8. Ahora, queremos saber un poco sobre su perspectiva respecto a cómo navegar el sistema de tutorías del estado. ¿Cómo ha sido la experiencia de su familia con ….

- las tutorías y los defensores que actúan como tutores?

    - ¿Lo han aplicado? ¿Cómo lo entienden? ¿Cuál es su experiencia respecto a cómo organizarlo o utilizarlos?
  - la toma de decisiones con apoyo?
    - ¿Lo han aplicado? ¿Cómo lo entienden? ¿Cuál es su experiencia respecto a cómo organizarlo o utilizarlos?
- otras opciones a la tutoría, tales como: Representantes o apoderados para los cuidados de salud; poderes legales; Representante del beneficiario
    - ¿Lo han aplicado? ¿Cómo lo entienden? ¿Cuál es su experiencia respecto a cómo organizarlo o utilizarlos?

9. ¿Por qué decidió solicitar, o no solicitar, la tutoría?

10. ¿Cuán satisfecho está con el sistema de tutorías de Florida?
    - ¿Qué le gusta o no le gusta respecto a este sistema?
    - ¿Cómo se podría mejorar?

¡Gracias a todos por compartir lo que piensan y sus ideas con nosotros el día de hoy! Reiteramos que nos daremos a conocer sus nombres y que la información que han compartido se mantendrá de manera privada y confidencial. Les recordamos nuestra solicitud de que ninguno de ustedes comparta la información que escuchó hoy, ni los nombres de las personas presentes en la sesión. De nuevo, ¡gracias!

Appendix D. Focus Group Guide: People with Intellectual and Developmental Disabilities (English)

Moderator: (Moderator introduce self and give your relation to disability (e.g. family member, researcher, advocate)

Thank you for coming today. We want to learn how you and your family thrive. Thriving is when you are at your best in every way. That could be feeling happy, feeling good about yourself, and feeling like things are going well for you. Sometimes people have bad days, but we want to know what helps you have good days.

We want to hear all of your ideas. There is no wrong answer. Whatever you have to share, please feel free.

We want to know 3 big things
1. How does your family help you thrive?
2. What else helps you thrive?
3. What helps your family thrive?

We want to hear anything you want to share with us. We want to learn from you about your family and life.

We are going to record this talk so we can listen to it again later. But we will not tell anyone who said what and we won't share your name or any information that identifies you. After we listen later, we will delete the recording to keep your name confidential.

We also want everyone here to keep the information you hear today confidential. Please do not tell people the names of anyone else here. Please do not share what other people here talked about once we are done. Remember that sometimes people make mistakes. People here might talk about what was said, so we cannot be totally sure what you share will remain private.

When you want to talk, raise your hand. When it is your turn, tell us your name. Every time you talk, please tell us your name again.

Now we are going to start.

This focus group is being conducted for the Strive to Thrive Project on _______[DATE] by ________________________________(MODERATOR(s)).

START TIME - _____________.
Let's start by introducing ourselves.
1.Please tell us your first name only and what you think of when you hear the word "thriving"?

When we talk about thriving, we mean: Being happy and healthy. Having people in your life that are important to you and care about you. Doing your best every day.

2.How does your family help you thrive?

- What does your family do to help you feel happy and fulfilled in life?
- Is there anything you <u>wish your family did differently</u> to help you feel happy and have a good life?
- How does your family help you make choices? What kind of <u>choices does your family help you make</u>?
- What kind of <u>choices do you want to make</u> for yourself in the future?

3.You talked a lot about how your family helps you thrive. What ELSE (besides your family) helps you thrive?

- What helps you do well and feel good about yourself?

4.We talked about what helps you thrive, now I want to ask: What helps YOUR FAMILY thrive?

- What are some things that help your family thrive?

5.How could Florida's programs and policies help you and your family thrive?

- How could future planning programs help you and your family thrive? (i.e. planning for when your family members are no longer able to provide care.)

6.Is there anything else you want to add or say about thriving?

Now, we want to learn a bit about your perspective on the state guardianship system.

7.What do you know about guardianship?

- Where have you heard the word "guardianship"?
- What do you think a guardian should do for you?

8.Do you have a guardian?

- If yes, do you know who your guardian is?
- If yes, how do you feel about your guardian?
- If no, do you have someone who supports you in decision making?

9.How do you feel about guardianship?

- What do you like about having or not having a guardian?
- How do you think having a guardian, or not having a guardian, could be better?
- Are there some situations where it would be better for someone to make a decision FOR you? Or some situations where it would be better for someone to make a decision WITH you?
- What do you think about supported decision-making?

Thank you all for sharing your thoughts and ideas with us today! Again, we will not share any of your names. We will keep the information you shared confidential. As a reminder, please do not share the information you heard today or the names of people who shared today. Thank you again!

Appendix E. Focus Group Guide: People with Intellectual and Developmental Disabilities (Spanish)

Moderador: (El moderador se presenta y le indica a cada persona su relación con la discapacidad (por ejemplo, miembro de la familia, investigador, defensor, etc.)

Gracias por venir el día de hoy. Estamos estudiando qué puede ayudarle a usted y a su familia para que logren prosperar. Prosperar es cuando usted está en sus mejores condiciones, en todo sentido. Puede ser cuando se siente feliz, se siente bien consigo mismo, y siente que todo va bien para usted. Algunas veces, las personas tienen un mal día, pero lo que queremos saber es qué le puede ayudar a tener un buen día.

Queremos escuchar todas sus ideas. No hay respuestas equivocadas. Sienta que tiene la libertad de compartir lo que quiera.

Queremos saber 3 cosas muy importantes

1. ¿Cómo le ayuda su familia para que logre prosperar?
2. ¿Qué otra cosa le ayuda para que pueda prosperar?
3. ¿Qué puede ayudar a su familia para que logre prosperar?

Queremos escuchar todo lo que quiera compartir con nosotros. Queremos que nos cuente sobre su familia y su vida.

Vamos a grabar esta sesión para luego poder escucharla; pero no le diremos a nadie quién dijo qué, ni su nombre, ni ninguna información que le identifique. Después de volver a escuchar la grabación, se destruirá para mantener la confidencialidad de su nombre.

También pedimos a todos los del grupo que mantengan la información que escuchen hoy como confidencial. Por favor, no le digan a nadie los nombres de los demás participantes. Por favor, después que termine la sesión, no le digan a nadie lo que se habló aquí. Recuerde que, a veces, la gente comete errores y pueden comentar lo que se dijo, de manera que no podemos estar totalmente seguros que se mantenga la privacidad de que lo que usted diga.

Cuando quiera hablar, levante la mano. Cuando llegue su turno, diga su nombre y luego; por favor, repítalo cada vez que hable.

Ahora vamos a comenzar.

Este focus group se lleva a cabo para el Proyecto *Strive to Thrive* (los esfuerzos por prosperar) el día _______[FECHA] y está dirigido por ______________________________(MODERADOR(es)).

HORA DE INICIO - ____________.

Comencemos con las presentaciones.

1. Por favor, indique solo su primer nombre y lo primero que piensa cuando escucha la palabra “prosperar”.

Cuando hablamos de prosperar nos referimos a estar feliz y saludable. A tener gente en su vida que es importante para usted y se preocupa por usted. Es estar en las mejores condiciones, todos los días.

2. Su familia, ¿cómo le ayuda para que logre prosperar?

- ¿Qué hace su familia para ayudar a que usted se sienta feliz y satisfecho con su vida?
- ¿Hay algo que usted <u>desea que su familia haga de una forma distinta</u> para ayudar a que usted se sienta feliz y tenga una vida agradable?
- ¿Cómo le ayuda su familia cuando usted tiene que elegir entre varias opciones? ¿Qué tipo de elecciones <u>le ayuda a hacer su familia</u>?
- En el futuro, ¿qué tipo de <u>elecciones le gustaría hacer por usted mismo</u>?

3. Ya habló bastante sobre la forma en que su familia le ayuda para que logre prosperar. ¿Qué OTRA COSA (aparte de su familia) le ayuda para que logre prosperar?

- ¿Qué le ayuda a estar bien y sentirse bien consigo mismo?

4. Ya hablamos sobre lo que le ayuda para que logre prosperar, ahora quiero preguntarle: ¿Qué ayuda a SU FAMILIA para que logre prosperar?

- ¿Cuáles serían algunas de las cosas que ayudan a su familia para que pueda prosperar?

5. Los programas y políticas de Florida, ¿cómo pueden ayudarle a usted y a su familia para que logren prosperar?

- Los programas que se planifiquen para el futuro, ¿cómo podrían ayudarle a usted y a su familia para que logren prosperar? (por ejemplo, planificar para cuando los miembros de su familia, ya no le puedan brindar cuidados).

6. ¿Hay algo más que quiera agregar sobre cómo prosperar?

Ahora, queremos conocer un poco cuál es su perspectiva respecto al sistema de tutorías del estado.

7. ¿Qué sabe usted sobre la tutoría?

  - ¿Dónde ha escuchado la palabra “tutoría”?
  - ¿Qué cree que un tutor podría hacer por usted?

8. ¿Usted tiene un tutor?

  - Si es así, ¿sabe quién es su tutor?
  - Si es así, ¿cómo se siente respecto a su tutor?
  - Si no es así, ¿tiene a alguien que le brinde apoyo en la toma de decisiones?

9. ¿Cómo se siente respecto a la tutoría?
    - ¿Qué le gusta de tener o no tener un tutor?
    - ¿Cómo cree que sería mejor si tiene o no tiene un tutor?
    - ¿Hay alguna situación donde cree que sería mejor que otra persona tome una decisión POR usted? O ¿hay alguna situación donde cree que sería mejor que alguien tome una decisión en conjunto CON usted?
    - ¿Qué piensa de la toma de decisiones con apoyo?

¡Gracias a todos por compartir lo que piensan y sus ideas con nosotros el día de hoy! Reiteramos que no daremos a conocer sus nombres y que la información que han compartido se mantendrá de manera confidencial. Les recordamos nuestra solicitud de que ninguno de ustedes comparta la información que escuchó hoy, ni los nombres de las personas presentes en la sesión. De nuevo, ¡gracias!

Appendix F. Online Survey (English)

Section 1: Caregiving Scope

Welcome to the Strive to Thrive survey!

If you are an aging family caregiver (over age 50) of an individual with an intellectual or developmental disability (I/DD) who lives in Florida, we want to learn how you maintain a positive quality of life both at home and in the community. We know that often family caregivers in the DD community are similar yet are unique in many ways.

We want to understand the positive resources and approaches you use every day to not just survive but thrive. **"Thriving is the state of positive functioning at its fullest range—mentally physically, and socially" (Su et al., 2014)**

We define thriving as the act of flourishing on a day-to-day basis and having a fulfilling life. The information you share will be used to encourage other I/DD families to thrive on their caregiving journeys.

We appreciate your willingness to complete this survey and help us meet that goal.

1a. Do you live in Florida?

☐ Yes
☐ No

[Logic: if no, cease survey administration and provide the following text: "Thank you for your interest, but you do not meet the qualifications for this survey. We are gathering information about experienced family caregivers in Florida over the age of 50." If yes: display 1b]

1b. What county do you live in?

[drop down list of 67 counties]

2. What is your age?__________________

[Logic: if age <50, cease survey administration and provide the following text: "Thank you for your interest, but you do not meet the qualifications for this survey. We are gathering information about experienced family caregivers in Florida over the age of 50."]

3. What is your relationship to the individual with an I/DD?

☐ Parent
☐ Sibling
☐ Grandparent
☐ Other (Please specify) ____________________________

4. Where does your family member with IDD live?

☐ In my household
☐ on his/her own (Apartment/Home)

☐ with family or friend(s) or guardian(s) other than myself
☐ in supportive living (6 people or less)
☐ in a group home
☐ in a foster home
☐ in a private/public institutional setting (intermediate care facility, developmental center, adult congregate living, nursing facility or other residential setting)
☐ Other (Please specify): ______________________________
[Logic: if “living in my household” is not selected in 3a, display question 3b]

4b. How often do you see your family member in-person?

☐ Daily
☐ More than once a week
☐ Once a week
☐ A few times a month
☐ Once a month
☐ A few times a year
☐ Once a year or less

5. In a typical week about how much time do you spend providing help to the individual with IDD (Such as dressing, shopping, giving advice, etc.)

____

6. How often do you <u>call/text/email/FaceTime</u> your family member?

☐ Daily
☐ Once a week
☐ Once a month
☐ A few times a year
☐ Once a year or less
☐ Never

7a. What is the typical daily activity of your family member with IDD?

☐ Employed full or part time
☐ Attends school or classes
☐ Participates in a day program
☐ Volunteers
☐ At home with me
☐ Other: (please describe) __________________

8. What supports do you provide for the person with IDD? (Check all that apply)

☐ Physical support (help bathing, dental care, dressing, eating, etc.)
☐ Emotional support
☐ Financial support (shopping, banking, etc.)
☐ Behavioral support
☐ Provide social support

☐ Provide communication support
☐ Help navigate services and supports
☐ Other: (please specify)

9. Number of people that live in the household including yourself? (Fill in the blank)

____

10. Do you get any pay for your caregiving role? ~~(select one)~~
☐ Yes
☐ No

[Logic: If 9a=Yes, display 9b]

10b. How do you get paid for your caregiving role? (e.g. DD waiver, LTSS waiver, long-term care insurance, etc.)

____

11a. Do you have more than one individual for whom you provide care?

☐ Yes
☐ No

[Logic: If 11= "Yes," 11b appears]

11b. Please describe the relationship, age, living arrangement, disability of your additional family member(s) below.

☐

12. Does your family member exhibit any of the following behaviors?
☐ Aggression toward others (e.g., hitting, biting, kicking)
☐ Destructive/disruptive behaviors (e.g., breaking windows, screaming, etc.)
☐ Aggression toward self (e.g., self-injurious behavior including biting, self-hitting, head banging)
☐ None of these

13. Are you receiving the following types of services or support for your family member? For each service listed below, indicate whether you need this kind of help AND if so whether you are receiving this help (including private pay)

	Do you need this help?		**Are you receiving this help?**	
	Yes	No	Yes	No
In-home and/or out-of-home respite care (provides someone to look after your relative				

at home to provide you a break or enables you to temporarily place your relative in a residential program)				
In-home nursing and/or home care services (such as a housekeeper, health aide, or personal attendant)				
Specialized therapy and/or clinical services for your relative (such as physical, occupational, psychological or speech therapy)				
Structured programs outside the home (such as educational or vocational training or recreational activities)				
Employment supports (to assist your relative in obtaining and maintain a job in the community)				
Transportation for your relative				
Case management (helps you find appropriate services)				

Section 2: Scales

14. Thinking about YOURSELF (not your family member with IDD), please indicate your agreement or disagreement with each of the following statements using the scale below:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
There are people who appreciate me as a person					
I feel a sense of belonging in my community					
In most activities I do, I feel energized					
I am achieving most of my goals					
I can succeed if I put my mind to it					
What I do in life is valuable and worthwhile					
My life has a clear sense of purpose					
I am optimistic about my future					
My life is going well					
I feel good most of the time					

15. Please indicate your agreement or disagreement with each item below:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
There are people in my life who pay attention to my feelings and problems					
There are people in my life who appreciate what I do					
There are people in my life who I can get help from if I need it					
There are people in my life who I can talk to about how to handle things					

16. Please indicate your agreement or disagreement with each item below:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I find time for outside interests or hobbies of my own					
I am involved with other I/DD families locally or statewide					
I connect with friends and family via social media					
I make it a point to regularly attend religious, social, cultural or recreational events on my own					
I can meet my own needs for healthcare and relaxation					

17. Please indicate how much you agree with the following statements about your family member with IDD's effect on your life.

	Strongly Disagree	Disagree	Agree	Strongly Agree
I would make a fine model for a parent of a child with a disability				
I feel I can manage my relative's behavior				
I meet my own expectations in caring for my relative				
If anyone can find the answer to what is troubling my relative, I can				
I honestly believe I have the skills necessary to be a good caregiver to my relative				
My relative's pleasure over some little thing gives me pleasure				
My relative shows real appreciation for what I do for him/her				
Taking responsibility for my relative gives my self-esteem a boost				
Helping my relative helps me feel close to her/him				
I really enjoy being with my relative				
I feel that what I do can help improve my relative's situation				

Section 3: Thriving

18. Have you helped your family member in the following ways in the past year?

	Not at all	Sometimes	Most of the Time	N/A
Make social connections with friends				
Engage with other family members				
Advocate or speak up for what they want and need				
Navigate formal services and supports				
Participate in mindfulness or religious activities to help them express their spirituality				
Maintain healthy habits				
Be self-determined and make their own choices				
Transportation				

19. In which of the following ways does your family member with IDD help you?

☐ Helps me feel better when upset
☐ Helps me with my personal care
☐ Helps with household chores
☐ Helps financially
☐ Keeps me from feeling lonely
☐ Shares enjoyable time and activities with me
☐ Shares new useful advice and information

20. Did the following help you and/or your family member to thrive in the past year?

	Yes	**No**	**N/A**
Help from friends			
Help from family			
Help from paid staff (i.e. support workers, teachers, case managers, day program staff)			
Regular Exercise			
Eating healthy			
Healthcare (i.e. to go to doctors and other healthcare professionals; taking medication)			
Taking medication			
Participating in leisure activities (actively			

choosing to do things for yourself)			
Mindfulness activities (e.g. yoga, meditation)			
Religious or spiritual activities (e.g. attending worship services, prayer)			
Counseling or therapy sessions			
Peer support (e.g., self-advocacy groups, sport teams, family support groups)			
Sibling support (brothers & sisters of your family member with IDD)			
Making future plans (e.g. legal, financial, residential)			
Technology supports (iPad, phone, communication device, etc.)			
Transportation			

21. Is there anything else you'd like to share about what helps you and/or your family member with IDD thrive?

Section 4: Survey Respondent Demographics

22. What is your marital status? (Select one)

☐ Married
☐ Widowed
☐ Divorced/Separated
☐ I prefer not to answer

23. What is your race/ethnicity? (Check all that apply)

☐ American Indian/Alaska Native
☐ Asian
☐ Black/African American
☐ Native American/Pacific Islander
☐ White
☐ Two or more races
☐ Hispanic/Latino
☐ Other (Please specify) ______________________________
☐ I prefer not to answer

[Logic: if 23a= "Hispanic/Latino," display 23b…What is the reason for this specificity? And where are Central American countries?]

23b. If Hispanic/Latino, please specify background: (Check all that apply)

☐ Cuban

    ☐ Mexican
    ☐ Puerto Rican
    ☐ South American
    ☐ Dominican/Haitian
    ☐ Other (Please specify) ____________________________
    ☐ I prefer not to answer

24. Do you believe your physical health affects your caregiver role?

☐ Yes
  ☐ [Logic: If “yes”: Please explain: ____________]
☐ No

☐ **25. Do you believe your mental health affects your caregiver role?**

☐ Yes
  ☐ [Logic: If “yes”: Please explain: ____________]
☐ No

26. Which of the following best represents how you think of yourself? (Select one)

☐ Lesbian or gay
☐ Straight, that is, not gay or lesbian
☐ Bisexual
☐ Two-Spirit (If American Indian or Alaska Native)
☐ I use a different term than any described above.
  If checked, please describe: ____________________________________
☐ I don’t know
☐ I prefer not to answer

27. What is your current gender? (Select one)

☐ Male
☐ Female
☐ Non-binary (do not identify as either male or female)
☐ Transgender
☐ I use a different term than any described above.
If checked, please describe: ____________________________________
☐ Prefer not to answer

28. What is the highest level of education you have completed? (Select one)

☐ Some high school, no diploma
☐ High school diploma or GED
☐ Some college, no degree
☐ Associate’s (2-year) degree
☐ Bachelor’s (4-year) degree
☐ Master’s degree
☐ Doctoral degree or equivalent (e.g., Law school graduate)

29. What is your current employment situation? (Select one)

☐ Employed full-time
☐ Employed part-time
☐ Retired
☐ Unemployed
☐ I prefer not to answer

30. What is your total annual household income? (Select one)
☐ $0-$30,000
☐ $31,000-$60,000
☐ $61,000-$90,000
☐ $91,000-$120,000
☐ $120,000+
☐ I prefer not to answer

Section 5: Demographics for Family Member with IDD

31. What is the age of your family member with an IDD? (Fill in the blank)

____

32. What is the gender of your family member with IDD? (Select one)
☐ Man
☐ Woman
☐ Non-binary
☐ Two-Spirit (If American Indian or Alaska Native)
☐ I use a different term than any described above.
———If checked, please describe: ____________________________________
☐ I prefer not to answer

33. What is the race/ethnicity of your family member with IDD? (Check all that apply)
☐ American Indian/Alaska Native
☐ Asian
☐ Black/African American
☐ Native American/Pacific Islander
☐ White
☐ Two or more races
☐ Hispanic/Latino
☐ Other (Please specify) ______________________________
☐ I prefer not to answer

[Logic: If 31a= "Hispanic/Latino," display 31b]

33b. If Hispanic/Latino, please specify background: (Check all that apply)
☐ Cuban
☐ Mexican
☐ Puerto Rican
☐ South American

☐ Dominican
☐ Other (Please specify) ______________________________
☐ I prefer not to answer

34. What disabilities does your family member have? (Check all that apply)

☐ Intellectual disability
☐ Autism spectrum disorder
☐ Cerebral palsy
☐ Down syndrome
☐ Physical disability
☐ Mental illness/Psychiatric disorder
☐ Sensory disability (e.g. blind or deaf)
☐ Spina bifida
☐ Phelan McDermid
☐ Other disability (Please specify) ______________________________

35. What is the level of intellectual disability of your family member with IDD? (Select one)

☐ Mild
☐ Moderate
☐ Severe
☐ Profound
☐ Unknown

36. What is your family member's preferred means of communication?

☐ Spoken
☐ Gestures/body language
☐ Sign language/finger spelling
☐ Communication aid or device

37a. Who else provides support for the individual with IDD? (Check all that apply)

☐ My parents
☐ My siblings
☐ My friends
☐ My other children
☐ N/A
☐ Paid support staff
☐ Other (Please specify) ______________________________

[Logic: Each item in 37a marked "Yes," will appear as part of the matrix for 37b; If 37a= "N/A," 37b will not display]

37b. Please share the approximate number of hours per week that support is provided and indicate if the person is getting paid and by whom:

My parents	Approximate number of hours per week:

	___________
My siblings	Approximate number of hours per week: ___________
My friends	Approximate number of hours per week: ___________
My other children	Approximate number of hours per week: ___________
Paid support staff	Approximate number of hours per week: ___________
Other:	Please Specify: ______________________________ Approximate number of hours per week: ___________

38a. Does your family member with IDD have a legal guardian? (Select one)

- ☐ Yes
- ☐ No

[Logic: If 38a is marked "Yes," 38b appears]

38b. If yes, who is their legal guardian? (Check all that apply)

- ☐ Yourself
- ☐ Parent
- ☐ Sibling
- ☐ Other family member
- ☐ Friend
- ☐ State appointed guardian
- ☐ Other: (Please specify) ___________________________

39. Does receiving formal services help you thrive (e.g. ~~in home or out of home~~ respite care, nursing care, specialized therapy or clinical services, structured programs outside the home, employment supports)?

- ☐ Yes
  - ☐ [Logic: If "yes": Please specify: _________]
- ☐ No
- ☐ NA (we do not receive formal services)

40. What effect does your family member with IDD have on your life? Please explain.

41. Is there anything else you would like to share about what helps your family to thrive?

Thank you so much for your responses!

Appendix G. Online Survey (Spanish)

Sección 1: Alcance del Cuidado

¡Bienvenido/a a la encuesta ¡Luchar para Prosperar! (**Strive to Thrive**!)

Si usted es un/a cuidador/a familiar de edad avanzada (mayor de 50 años) de una persona con una discapacidad intelectual o del desarrollo (I/DD) que vive en Florida, queremos conocer cómo mantiene una calidad de vida positiva tanto en el hogar como en la comunidad. Sabemos que los cuidadores familiares en la comunidad de personas con discapacidades del desarrollo pueden compartir muchas experiencias, pero también son únicos en muchos aspectos.

Queremos comprender los recursos positivos y los enfoques que utiliza cada día para no solo sobrevivir, sino prosperar. **“Prosperar es el estado de funcionamiento positivo en su máxima expresión, tanto mental, física como socialmente”**(Su et al., 2014).

Definimos **prosperar** como el acto de florecer en el día a día y tener una vida plena. La información que comparta se utilizará para motivar a otras familias de personas con I/DD a prosperar en su camino como cuidadores.

Agradecemos su disposición para completar esta encuesta y ayudarnos a alcanzar este objetivo.

1a. ¿Vive en Florida?

☐ Yes
☐ No

[Lógica: Si la respuesta es "No", finalizar la administración de la encuesta y mostrar el siguiente mensaje: "Gracias por su interés, pero no cumple con los requisitos para esta encuesta. Estamos recopilando información sobre cuidadores familiares con experiencia en Florida mayores de 50 años."

Si la respuesta es "Sí", mostrar la pregunta 1b.

1b. ¿En qué condado de Florida vive?

____

2. ¿Qué edad tiene? (Llene el espacio en blanco)

____

☐ Prefiero no contestar

[Por favor, tenga en cuenta que no necesitamos encuestas de cuidadores que tengan menos de 50 años]

3. ¿Cuál es su relación con la persona con discapacidad intelectual o de desarrollo? (DID)?

☐ Padre/Madre
☐ Hermano
☐ Abuelo
☐ Otra (Por favor, especifique)

____

4. ¿Cómo es la situación de vivienda del miembro de su familia con DID?
(Seleccione una opción)

☐ Vive en mi casa
☐ Vive en su propio (Apartamento/ Casa)
☐ Vive con la familia, amigo(s) / tutor(es)
☐ Vive en una instalación con apoyo (para 6 personas o menos)
☐ Vive en una residencia grupal
☐ Vive con una familia de acogida o anfitriona
☐ Vive en un entorno institucional privado o público, sede de cuidados intermedios, centro de desarrollo, en una vivienda colectiva para adultos, un hogar de ancianos, o algún otro entorno residencial (para 16 personas o más)
☐ Otro (Por favor, especifique): __________________________

[Si su respuesta es "vive en mi casa" pase a la pregunta 4b]

4b. [SI NO VIVE EN SU CASA] En promedio, ¿cuán a menudo ve usted al miembro de su familia, en persona, en un mes/año normal? *(Seleccione una opción)*

☐ Diariamente
☐ Más de una vez a la semana
☐ Una vez a la semana
☐ Unas pocas veces al mes
☐ Una vez al mes
☐ Unas pocas veces al año
☐ Una vez al año, o menos

5. En una semana normal, indique más o menos cuánto tiempo pasa usted brindando ayuda a la persona con DID (por ejemplo, para vestirse, ir de compras, darle recomendaciones, coordinar servicios, etc.)

____

6. En promedio, ¿cuán a menudo llama o le envía un texto a, o habla por chat en vivo con (FaceTime, Snapchat, WhatsApp, etc.) el miembro de su familia?
(Seleccione una opción)

☐ Diariamente
☐ Más de una vez a la semana
☐ Una vez a la semana
☐ Unas pocas veces al mes

☐ Una vez al mes
☐ Unas pocas veces al año
☐ Una vez al año, o menos

7. ¿Cuál es la situación laboral del miembro de su familia con DID? *(Seleccione todas las opciones que apliquen)*

☐ Empleado(a) a tiempo completo o parcial
☐ Asiste a la escuela o a clases
☐ Participa en un programa diurno
☐ Es voluntario
☐ Actualmente, no trabaja
☐ Otra (por favor, descríbala): ____

____

8. En su rol de cuidador, ¿qué hace usted para la persona con DID? *(Seleccione todas las opciones que apliquen)*

☐ Le brinda apoyo físico (le ayuda a bañarse, cuidado dental, vestirse, comer, etc.)
☐ Le brinda apoyo emocional
☐ Le brinda apoyo financiero
☐ Le brinda apoyo respecto a su conducta
☐ Le brinda apoyo social
☐ Le apoyo en la comunicación
☐ Le ayuda a navegar por los distintos servicios y apoyos
☐ Otro: (Por favor, especifique): ______________________________

9. Cantidad de personas que viven en su casa, incluyéndole a usted:

____

10. A usted, ¿le pagan por su rol como cuidador? (Seleccione una opción)

☐ Sí
☐ No

[Si la respuesta es “no”, pase a la pregunta 11]

10b. ¿Cómo le pagan por su rol de cuidador? (por ejemplo, una exención por DD, exención por servicios y apoyo a largo plazo (LTSS), seguro por cuidados a largo plazo, etc.)

____

11a. Usted, ¿es cuidador de más de una persona? (por ejemplo, padre o madre de edad avanzada, otro niño menor de 18 años o con una discapacidad, un cónyuge con demencia)

☐ Sí
☐ No

[Si la respuesta es “no”, pase a la pregunta 11a]

11b. Si aplica, por favor proporcione más detalles sobre la otra persona a la que cuida (por ejemplo, su relación con usted, edad, situación de vivienda, estatus de discapacidad, estatus laboral).____

12. El miembro de su familia, ¿refleja alguna de las siguientes conductas?

☐ Agresión contra otras personas (por ejemplo, golpes, mordiscos, patadas)
☐ Conductas destructivas o disruptivas (por ejemplo, romper ventanas, gritar, etc.)
☐ Agresiones contra sí mismo (por ejemplo, conductas autodestructivas, incluyendo, mordiscos, pegarse a sí mismo, golpearse en la cabeza)
☐ Ninguna de ellas

13. ¿Está recibiendo los siguientes tipos de servicios o apoyo para su familiar? Para cada servicio enumerado a continuación, indique si necesita este tipo de ayuda Y si la está recibiendo (incluyendo pagos privados).

	¿Necesita esta ayuda con lo siguiente?		**¿Está recibiendo esta ayuda?**	
	Sí	No	Sí	No
Cuidado de relevo en el hogar y/o fuera del hogar (proporciona a alguien que cuide a su familiar en casa para darle un descanso o le permite colocar temporalmente a su familiar en un programa residencial)				
Servicios de enfermería en el hogar y/o de cuidado en el hogar (como ama de llaves, asistente de salud o asistente personal).				
Servicios especializados de terapia y/o clínicos para su familiar (como terapia física, ocupacional, psicológica o del habla).				
Programas estructurados fuera del hogar (como actividades educativas, de formación vocacional o recreativas).				
Apoyos para el empleo (para ayudar a su familiar a obtener y mantener un trabajo en la comunidad).				
Transporte para su familiar.				
Gestión de casos (le ayuda a encontrar servicios apropiados).				

14. Pensando en USTED (no en su familiar con discapacidad intelectual o del desarrollo - IDD), indique su grado de acuerdo o desacuerdo con las siguientes afirmaciones utilizando la escala a continuación:

	Muy en desacuerdo	En desacuerdo	Ni de acuerdo ni en desacuerdo	De acuerdo	Muy de acuerdo
Esta es gente que me aprecia como persona					
Tengo un sentido de pertenencia respecto a mi comunidad					
En la mayoría de actividades que llevo a cabo, me siento con más					
Siempre aprendo algo cada día					
Estoy logrando la mayoría de mis metas					
Puedo tener éxito si me concentro en ello					
Lo que hago en la vida es valioso y vale la pena					
Mi vida tiene un claro sentido de motivación					
Soy optimista respecto a mi futuro					
Mi vida va muy bien					
La mayoría del tiempo me siento bien					

15. Por favor indique si está de acuerdo o en desacuerdo con estas frases, utilizando siguiente escala:

	Muy de acuerdo	De acuerdo	Neutro	En desacuerdo	Muy en desacuerdo
En mi vida hay mucha gente que está pendiente de mis sentimientos y problemas					
En mi vida hay mucha gente que aprecia lo que hago					
En mi vida hay mucha gente a la que le puedo pedir ayuda cuando lo necesite					
En mi vida hay mucha gente con quienes puedo hablar sobre cómo manejar las cosas					

16. Indique su grado de acuerdo o desacuerdo con cada uno de los siguientes enunciados:

	Totalmente en desacuerdo	**En desacuerdo**	**Ni de acuerdo ni en desacuerdo**	**De acuerdo**	**Totalmente de acuerdo**
Encuentro tiempo para intereses o pasatiempos fuera de mi hogar.					
Estoy involucrado/a con otras familias con discapacidades intelectuales y del desarrollo (I/DD) a nivel local o estatal.					
Me conecto con amigos y familiares a través de las redes sociales.					
Me aseguro de asistir regularmente a eventos religiosos, sociales, culturales o recreativos por mi cuenta.					
Puedo satisfacer mis propias necesidades de atención médica y relajación					

17. Por favor, indique en qué medida está de acuerdo con las siguientes afirmaciones sobre el impacto de su familiar con discapacidades intelectuales y del desarrollo (IDD) en su vida.

	Totalmente en desacuerdo	**En desacuerdo**	**Totalmente de acuerdo**	**De acuerdo**
Sería un buen modelo para ser padre/madre de un niño con discapacidad.				
Siento que puedo manejar el comportamiento de mi familiar				
Cumplo con mis propias expectativas al cuidar a mi familiar				
Si alguien puede encontrar la respuesta a lo que está perturbando a mi familiar, soy yo				

17. (Continuada) Por favor, indique en qué medida está de acuerdo con las siguientes afirmaciones sobre el impacto de su familiar con discapacidades intelectuales y del desarrollo (IDD) en su vida.

Creo sinceramente que tengo las habilidades necesarias para ser un buen cuidador/a de mi familiar				
El placer de mi familiar por algo pequeño me da placer				
Mi familiar muestra una verdadera apreciación por lo que hago por él/ella.				
Asumir la responsabilidad de mi familiar me da un impulso en mi autoestima.				
Ayudar a mi familiar me hace sentir cercano/a a él/ella				
Disfruto realmente estar con mi familiar				
Siento que lo que hago puede mejorar la situación de mi familiar				

Sección 3: Prosperar

18. ¿Ha ayudado a su familiar en las siguientes maneras durante el último año?

	Nada en absoluto	**A veces**	**La mayor parte del tiempo**	**N/A**
Establecer conexiones sociales con amigos.				
Interactuar con otros miembros de la familia.				
Abogar o expresarse por lo que desean y necesitan.				
Navegar servicios y apoyos formales.				
Participar en actividades de atención plena o religiosas/ayudarlos a expresar su espiritualidad.				
Mantenerse saludable.				
Ser autodeterminado (apoyarlos para que tomen sus propias decisiones).				
Transporte.				

19. ¿De qué manera su familiar con una discapacidad intelectual y del desarrollo (IDD) lo ayuda a usted?

c Me ayuda a sentirme mejor cuando estoy molesto/a.
c Ayuda con el cuidado personal.
c Ayuda con las tareas del hogar.
c Ayuda económicamente.
c Me evita sentirme solo/a.
c Comparte actividades agradables conmigo.
c Me da consejos e información útiles.

20. ¿Le ayudaron los siguientes factores a usted y/o a su familiar a prosperar durante el último año?

	Sí	No	N/A
Ayuda de amigos			
Ayude de la familia			
Ayuda del personal pagado (por ejemplo, trabajadores de apoyo, maestros, gestores de casos, personal de programas diurnos)			

Ejercitarse regularmente			
Comer de manera saludable			
Atención médica (por ejemplo, visitar a médicos y otros profesionales de la salud)			
Tomar medicamentos			
Participar en actividades de ocio			
actividades de atención plena			
Actividades religiosas o espirituales (por ejemplo, asistir a servicios religiosos, orar			
Asesoramiento o sesiones de terapia			
Apoyo de pares (por ejemplo, grupos de autoabogacía, equipos deportivos, grupos de apoyo familiar)			
Sibling support (brothers & sisters of your family member with IDD)			
Tener planes futuros establecidos (por ejemplo, planes legales, financieros, residenciales)			
Apoyos tecnológicos (iPad, teléfono, dispositivo de comunicación, etc.)			
Transporte services			

21. ¿Hay recursos locales que le gustaría compartir sobre lo que ayuda a su familia a prosperar? (por ejemplo, programas en bibliotecas locales, universidades, iglesias, grupos cívicos o recreativos, ligas o juegos deportivos, etc.).

Sección 4: Datos Demográficos de los Participantes en la Encuesta

22. ¿Cuál es su estado civil? *(Seleccione una opción)*

☐ Casado
☐ Viudo
☐ Divorciado/Separado
☐ Nunca se ha casado
☐ Vive con su pareja
☐ Prefiero no contestar

23a. ¿Cuál es su origen racial o étnico? *(Seleccione todas las opciones que apliquen)*

☐ Indígena Norteamericano o Nativo de Alaska
☐ Asiático
☐ Afroamericano
☐ Nativo norteamericano o de una isla del Pacífico
☐ Blanco
☐ Dos o más orígenes raciales
☐ Hispano o latino
☐ Otro (Por favor, especifique) ____________________________
☐ Prefiero no contestar

[Si no es Hispano o Latino, pase a la pregunta 22]

23b. Si es Hispano o Latino, por favor especifique su procedencia: (Seleccione todas las opciones que apliquen)

☐ Cubano
☐ Mexicano
☐ Puertorriqueño
☐ Suramericano
☐ Dominicano/Haitianos
☐ Otro (Por favor, especifique) ____________________________
☐ Prefiero no contestar

24. ¿Cree que su salud física afecta su rol como cuidador?
☐ **Sí**
☐ **[Lógica: Si "sí": Por favor explique: ___________]**
☐ **No**
25. ¿Cree que su salud mental afecta su rol como cuidador?
☐ **Sí**
☐ **[Lógica: Si "sí": Por favor explique: ___________]**
☐ **No**

26. ¿Cuál de las siguientes opciones representa mejor cómo se considera usted?
(Seleccione una opción)

☐ Lesbiana u homosexual
☐ Heterosexual, es decir ni homosexual ni lesbiana

☐ Bisexual
☐ Uso un término distinto a los indicados arriba.
Si selecciona esta opción, por favor
indíquelo: ______________________________
☐ No sé
☐ Prefiero no contestar

27. Actualmente, ¿cuál es su sexo? *(Seleccione todas las opciones que apliquen)*

☐ Masculino
☐ Femenino
☐ No-binario (no se identifica ni como de sexo masculino ni como de sexo femenino)
☐ Transgénero
☐ Uso un término distinto a los indicados arriba.
Si selecciona esta opción, por favor indíquelo:
____
☐ Prefiero no contestar

28. ¿Cuál es el nivel de educación más alto que culminó? *(Seleccione una opción)*

☐ Parte de bachillerato, sin graduarme
☐ Graduado de bachillerato o de educación general (GED)
☐ Parte de la escuela superior, sin graduarme
☐ Graduado de Asociado (2 años)
☐ Graduado de Licenciado (4 años)
☐ Graduado de Maestría
☐ Graduado de Doctorado o su equivalente (por ejemplo, graduado de la Escuela de Derecho)

29. Actualmente, ¿cuál es su situación laboral? *(Seleccione todas las opciones que apliquen)*

☐ Empleado a tiempo completo
☐ Empleado a tiempo parcial
☐ Retirado
☐ Desempleado
☐ Prefiero no contestar

30. ¿Cuál es el ingreso total anual de su hogar? (Seleccione una opción)

☐ $0-$30.000
☐ $31.000-$60.000
☐ $61.000-$90.000
☐ $91.000-$120.000
☐ $120.000+
☐ Prefiero no contestar

Sección 5: Datos Demográficos del Miembro de la Familia con DID

31. ¿Qué edad tiene el miembro de su familia con DID?

____

32. ¿Cuál es el sexo del miembro de su familia con DID? (Seleccione todas las opciones que apliquen)

☐ Masculino
☐ Femenino
☐ No-binario (no se identifica ni como de sexo masculino ni como de sexo femenino)
☐ Transgénero
☐ Uso un término distinto a los indicados arriba.
☐ Si selecciona esta opción, por favor indíquelo:

____

33a. ¿Cuál es el origen racial o étnico del miembro de su familia con DID? (Seleccione todas las opciones que apliquen)

☐ Indígena Norteamericano o Nativo de Alaska
☐ Asiático
☐ Afroamericano
☐ Nativo Norteamericano o de una Isla de Pacífico
☐ Blanco
☐ Dos o más orígenes raciales
☐ Hispano o latino
☐ Otro (Por favor, especifique) ______________________________
☐ Prefiero no contestar

[Si no es Hispano o Latino, pase a la pregunta 33]

33b. Si es Hispano o Latino, por favor especifique su procedencia: (Seleccione todas las opciones que apliquen)

☐ Cubano
☐ Mexicano
☐ Puertorriqueño
☐ Suramericano
☐ Dominicano/Haitianos
☐ Otra (Por favor, especifique) ______________________________
☐ Prefiero no contestar

34. ¿Qué discapacidades tiene el miembro de su familia? *(Seleccione todas las opciones que apliquen)*

☐ Discapacidad intelectual
☐ Trastorno del espectro autista
☐ Parálisis cerebral
☐ Síndrome de Down
☐ Discapacidad física
☐ Enfermedad mental/ trastorno psiquiátrico

☐ Discapacidad sensorial (por ejemplo, ciego o sordo)
☐ Espina bífida
☐ Phelan McDermid
☐ Otra discapacidad (Por favor, especifique) ___________________________

35. ¿Cuál es el nivel de discapacidad intelectual que tiene el miembro de su familia con DID? (Seleccione una opción)

☐ Leve
☐ Moderado
☐ Severo
☐ Profundo
☐ N/A - Ninguno disponible

36. ¿Cuál es el medio de comunicación que prefiere el miembro de su familia?

☐ Hablar
☐ Gestos/ lenguaje corporal
☐ Lenguaje por señas / alfabeto manual
☐ Ayuda o dispositivo de comunicación
☐ No-verbal

37. ¿Quién más, de su familia ampliada o red de soporte, también le brinda apoyo a la persona con DID? *(Seleccione todas las opciones que apliquen)*

☐ Mis padres

☐ Mis hermanos

☐ Mis amigos

☐ Mis otros hijos

☐ N/A - Ninguno disponible

☐ Personal de apoyo remunerado

☐ Otro (Por favor, especifique): ____________________

37b. Por favor, comparta el número aproximado de horas por semana que se proporciona apoyo e indique si la persona está recibiendo pago y por quién:

Mis padres	Número aproximado de horas por semana: ___________
Mis hermanos	Número aproximado de horas por semana: ___________
Mis amigos	Número aproximado de horas por semana: ___________
Mis otros hijos	Número aproximado de horas por semana: ___________
Personbal de apoyo pagado	Número aproximado de horas por semana: ___________
Otrosr:	Por favor especifique: ______________________________ Número aproximado de horas por semana: __________

38a. El miembro de su familia con DID, ¿tiene un tutor legal? (Seleccione una opción)

☐ Sí
☐ No

[Si la respuesta es no, pase a la Sección 5]

38b. Si es así, ¿quién es su tutor? (Seleccione todas las opciones que apliquen)

☐ Yo mismo
☐ Uno de sus padres
☐ Uno de sus hermanos
☐ Otro miembro de la familia
☐ Uno amigo
Otro: (Por favor, especifique) ____________________________

39. ¿Recibir servicios formales le ayuda a prosperar (por ejemplo, cuidado de respiro, atención de enfermería, terapia especializada o servicios clínicos, programas estructurados fuera del hogar, apoyos para el empleo)?

☐Sí
☐ [Lógica: Si "sí": Por favor especifique: _________]
☐ No
☐ NA (no recibimos servicios formales)

40. ¿Qué efecto tiene su familiar con IDD en su vida? Por favor, explique.

41. ¿Hay algo más que le gustaría compartir sobre lo que ayuda a su familia a prosperar?

¡Muchas gracias por sus respuestas!