



Environmental Scan Report

Strive to Thrive:
Researching Aging Caregiving Families Project

Prepared for the Florida Developmental
Disabilities Council

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Executive Summary

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. The purpose of this environmental scan is to inform the development of a survey and focus group protocols that will be used to gather information and experiences of aging families of adults with IDD in Florida to understand what helps them thrive.

Thriving is defined as “the state of positive functioning at its fullest range—mentally, physically, and socially” (Su et al., 2014). 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 the continuum beyond surviving to truly having a fulfilling life and thriving in their communities.

Methods

An environmental scan of the peer-reviewed and grey literature was conducted on thriving across aging and intellectual and developmental disabilities (IDD). The literature search culminated in 76 peer-reviewed articles as well as 14 “grey literature” articles (i.e., non-peer reviewed literature) such as reports and research briefs. Codes and themes were identified from a detailed review of the selected articles.

Findings

The findings showed themes that emerged under two main categories: (1) Support needs and barriers/challenges for families of people with IDD, and (2) Resources and supports that help people with IDD and their families thrive.

Support Needs and Barriers/Challenges for Families of People with IDD

Support Needs for Caregiver Role. Family caregivers had numerous support needs related to their caregiving roles for the individual with IDD. This included needing support for stress, mental health, and coping mechanisms. The literature also detailed the chronic health conditions experienced by family caregivers. Additionally, family caregivers were impacted by family characteristics, structure, and dynamics. The social support needs as well as the impact from the relationship with individuals with IDD and sibling relationships were also reported.

Support Needs Related to Services. Family caregivers have support needs related to services, specifically needing more support to navigate services as well as healthcare transitions for the individual with IDD.

Information Support Needs. Parents and siblings of people with IDD need more information on the available supports and services to be able to access them and help them in their family caregiving role.

Financial Support Needs. Caregiving can have a cost and impact on families financially. Caregiving roles can reduce employment opportunities, which can lead to less income and savings.

Support Needs for Transitions of Care. Transitions of care have become more necessary as individuals with IDD are living longer and increasingly outliving their parents. In addition, caregivers themselves undergo transitions because of aging and physical challenges, leading to fears about the future of their family members with IDDs, the role of their non-disabled children in future caregiving and the worry about how to make their children independent.

Planning for Future/Long-Term Care Planning. The long-term health needs of families are impacted by the longevity of caring for an individual with IDD. Siblings often take on greater support and caregiving roles as parents age. Future planning is a stressful process for most families, and they need more support in this area.

Resources and Supports that Help People with IDD and their Families Thrive

Families: Resources and Supports

Social Supports for Families. Family caregivers that receive social support are more likely to thrive. This type of support includes sibling support, support from grandparents, leisure activities, and peer navigators.

Health & Psychosocial Health Supports for Families. Family caregivers have better health and psychosocial health outcomes when they receive targeted supports. Support from healthcare systems and psychosocial support programs have the potential to improve these outcomes.

Instrumental Supports for Families. Family caregivers had better outcomes when they received instrumental supports, including formal supports and self-directed supports. Also, support brokers were helpful to family caregivers. Additionally, support provided by individuals with IDD to their family caregivers made a difference. Finally, coordinated healthcare as well as counseling and peer support groups had a positive impact on family caregivers to help them thrive.

Future Planning Supports for Families. Planning for the future helps families achieve better outcomes. As parents age, often siblings become primary

caregivers and future planning helps with successful role transitions. Family caregivers of people with IDD encounter significant challenges in making future plans and need more support in this area.

Technological Supports. Technology, including remote supports, can assist the individuals with IDD and their caregivers to get the help they need. Digital literacy for family caregivers needs to be improved to help them access these supports.

Individuals With IDD: Resources and Supports

Social Supports for People With IDD. When people with IDD received social support, they were more likely to have better outcomes and thrive. This included natural support, family support, formal support, and social support. Also, mindfulness interventions were found to be beneficial. Additionally, religion/spirituality was helpful to some people. Finally, organizational supports provided positive outcomes for people with IDD.

Health & Psychosocial Health Supports for People With IDD. Targeted interventions could be developed to improve health. Tailored health support interventions should consider childhood adversity, psychosocial impact of accessibility issues, dependence on others, and social isolation. When individuals with IDD choose their own support services, they have shown evidence of positive psychosocial outcomes.

Self-Determination/Autonomy Supports for People With IDD. Participating in formal self-advocacy is a common source of pride for many individuals with IDD. Providing opportunities for learning and practicing skills related to self-determination contributed to empowering individuals with IDD. Natural support networks also play an important role in the self-determination of individuals with IDD, impacting autonomy and self-determination.

Employment Supports for People With IDD. Being employed has shown to positively influence the psychosocial health of individuals with IDD; instill a sense of pride, self-confidence, and self-esteem; and contribute significantly to overall flourishing, happiness, and well-being. Furthermore, the type of employment has shown to impact quality of life for individuals with IDD, with those engaged in competitive employment reporting higher scores and those unemployed ranking lowest.

Tools and Instruments Identified

As part of the literature search, research articles with tools or instruments (such as surveys or focus group protocols) were identified. A list of 175 instruments were

discovered. These tools will be reviewed as the next step to develop the survey and focus group protocols for this project. The research team will determine which questions or scales could be used or adapted for adults with IDD and their family caregivers.

Gaps Identified

There were three main gaps identified based on the environmental scan of the literature. It includes the following:

1. Inclusion of Multiple Family Perspectives—Most of the research studies reviewed focused on only one family member perspective, usually the mother and sometimes the siblings. There is a gap where more research is needed that includes more than one family perspective together as well as the need to include family perspectives that are under-reported such as fathers.
2. Longitudinal Methods—Most studies discussed the need for more longitudinal studies to understand how the experiences of families change over time.
3. Measuring Complex Concepts—Researching concepts such as stress, self-determination, thriving, and well-being are difficult because there are often not clear and agreed upon definitions of these concepts. There is a need to define these concepts more specifically and clearly.

Limitations of the Scan

1. The scan does not include an exhaustive review of the literature and some topics may have been missed in the search.
2. The scan included a smaller amount of “grey literature” articles (i.e., non peer-reviewed literature) and some grey literature may have been missed in the search.
3. Time constraints limited the number of peer-reviewed and grey literature articles that could have been reviewed.

Implications

Thriving as a Framework for Future Research, Practice, and Policy

Development. This project takes an innovative approach by using the lens of thriving to explore the experiences of people with IDD and their aging families. There are a limited number of programs and interventions that have been developed using a thriving framework. To understand what thriving looks like for people with IDD and their aging families, we need to measure thriving by identifying the indicators. Using or adapting the relevant instruments or scales within the instruments derived from the literature search, we will be able to capture predictors of thriving and their well-being and ways aging families of people with IDD could thrive.

Include Multiple Family Perspectives in Research. There is a need to include multiple family perspectives in research on adults with IDD and their aging families. Understanding a more holistic view from multiple family member perspectives will help target resources and supports for families or people with IDD in a more integrated manner.

Recognize Resource and Support Barriers. Families tend to provide informal unpaid care for their family members with IDD. Studies have shown that limited quality programs for adults with IDD, financial costs, and system navigation were all significant barriers to families receiving adequate support. There is a need to understand the systemic barriers that families face to accessing supports and services, with these systems consistently failing to meet families' needs.

Build on Previous Work that Bridges Aging and Disability. It is important to understand the value of bridging aging and disability networks. This project builds on the previous work, including Florida's AGEDD project, the Project of National Significance on Bridging Disability and Aging, and work related to the RAISE Act. We hope to learn new information using the innovative approach brought by the lens of thriving so that recommendations can be made to improve the lives of adults with IDD and their aging family caregivers.

Next Steps

The next steps for the project include the following:

- Create a comprehensive survey tool to use with families of people with IDD to capture what helps them thrive.
- Develop focus group protocols to use with adults with IDD and family caregivers to understand what helps them thrive now and in the future.
- Translate and culturally adapt the data collection instruments for Spanish speaking families.
- Pilot test the survey and the focus group protocols with family caregivers and adults with IDD, including Spanish speaking families.
- Recruit and collect data from over 300 participants, including aging family caregivers and adults with IDD on what helps them thrive.
- Provide recommendations for future initiatives to support families of people with IDD to thrive.
- Share results with relevant stakeholders to inform the development of resources that support aging families of people with IDD as they strive to thrive.

Introduction

“There are only four kinds of people in the world: Those that have been caregivers, those that are caregivers, those who will be caregivers, and those who will need caregivers.”

- Rosalyn Carter

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.

To fulfill one portion of the project’s larger goals, the research team conducted an environmental scan of the literature on thriving across the aging and IDD communities. Thriving can include improvement in quality of life, satisfaction, physical and mental health outcomes, increased social participation, and more. This report presents the results of the environmental scan. The goal of the environmental scan was to provide a search of the literature regarding topics that are directly relevant to the main purpose of the *Strive to Thrive* project.

Support from families is essential for all people to thrive throughout the course of their lives. For people with IDD, family often provides support from birth or young age and well into adulthood. Families can ensure the dignity and self-determination of people with IDD as they grow and develop over a lifetime. Families provide a plethora of support to people with IDD including the following: help to participate in community activities and feel a sense of belonging, emotional support throughout life, physical help with tasks, health and medical appointments, financial support, and navigating services (Arnold, 2022).

In Florida, 75% of adults with IDD live at home with families. Of these people, 31% reside with family caregivers over 60-years old. There are more adults with IDD living with aging family caregivers due to increased lifespan of adults with IDD, aging of the population, growing waiting lists and unmet needs for formal community-based services. With so many families in Florida providing support to people with IDD, only 21% of total IDD expenditures are spent on family support (Tanis et al., 2022)

Health and psycho-social well-being of family members of people with IDD is 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). With so many aging family caregivers of people with IDD, it is essential to support families across the aging and developmental disability (DD) networks. These two distinct systems, the aging system and the DD system, can be challenging for families to navigate to get what they need to thrive. The Florida Developmental Disabilities Council (FDDC) has identified aging caregivers as a priority area to focus on in their current 5-year State Plan.

Definition of Thriving

There is a long history of research related to thriving, without one clear and agreed upon definition of the term. Su and colleagues (2014) reviewed the literature on thriving and developed the following definition which we will use as the anchor for this study:

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

Seven dimensions of psychological well-being underpin this framework for thriving according to Su and colleagues (2014):

1. Subjective well-being where the individual feels positive about themselves and their life
2. Relationships that are supportive and meaningful
3. Engagement and interest in everyday activities
4. Having a meaningful purpose in life
5. Gaining a sense of mastery of a skill and feeling a sense of accomplishment
6. Feeling a sense of control and autonomy of own life
7. Being optimistic

There are both internal characteristics or personal enablers that seem to enhance thriving as well as external forces or contextual enablers that contribute to the extent an individual thrives (Brown et al., 2017).

Thriving is the act of flourishing and is on the opposite end of the continuum from surviving. Learning what helps families move on this continuum beyond surviving to truly having a fulfilling life and thriving in their communities holds promise to advance policies, practices, and systems that support aging families of adults with IDD. Thriving can include improvement in quality of life, satisfaction, physical and mental health outcomes, increased social participation, resilience, self-determination, self-actualization and more. Various life domains can be explored related to ways families thrive such as daily life and employment, community living, healthy living, happiness and more. It is about adults with IDD and their families leading fulfilling and meaningful lives that allow them to reach their full potential, contribute to their communities, and feel a sense of belonging.

Conceptualization of Thriving

Despite the stress experienced by many families of individuals with IDD, there is evidence of some families adapting well, being resilient, and thriving (Blacher & Baker, 2007; Gerstein et al., 2009; Greeff & Nolting, 2013; Herrman et al., 2011; Lafferty et al., 2015). Using “thriving” as a framework to examine the experiences of aging families of adults with IDD represents an innovative approach to understanding their perspectives. Traditional models have focused primarily on challenges, barriers, and deficits for families of adults with IDD. By contrast, the thriving framework shifts the focus to the positive aspects of life that help enhance a person’s well-being. This framework enables researchers to explore the multiple dimensions of the experiences of aging families of adults with IDD to better understand ways to support these families. Adopting a “thriving” lens reframes aging families’ perspectives from focusing on the basics of mere survival to understanding what truly helps them have lives worth living. It acknowledges the strengths, capabilities, and aspirations of individuals with IDD and their families. It also provides a better understanding of the structures of families that exhibit positive adaptation and manage caring processes with resilience and confidence. This innovative approach cultivates a deeper discernment of the aspects that contribute to the overall well-being of aging families.

The conceptual framework of “thriving” for aging families of adults with IDD provides a broad and overarching positive context that underscores various interconnected dimensions as mentioned above to promote well-being. The framework respects the diversity within the IDD community, builds cultural humility, and recognizes the need for tailored approaches to meet individual and family needs.

Methods

Internal Team Input

As part of the environmental scan, we reviewed the peer-reviewed and selected grey literature (non-academic literature). The research team scanned the social science peer-reviewed literature via five separate search strategies. A general search from the UIC library search page, and PubMed, Google Scholar, PsycINFO, and Scopus databases. The researchers conducted multiple team meetings and specific conversations with the leadership of Florida DD Council and the Aging Caregiver Task Force to brainstorm about the prioritization of topics for the scan and about what the overarching concepts of the study would be. The Task Force, comprising of a chair, a co-chair and members from communities, agencies, and organizations, serves as an overseer and advisor to staff on all Council-funded initiatives assigned to the Aging Caregivers Task Force. Based on these meetings and conversations, the research team came to a consensus on what would be the relevant synonyms of those concept terms and search terms to be included to conduct the environmental scan. The researchers also met with an Information Service and Liaison Librarian at the University of Illinois to finalize the databases utilized for the scanning process, and to discuss the four overarching concepts in more depth.

Table 1. Main Concepts of Environmental Scan

Concept	Synonymous Search Terms
Aging	Aging Geriatric* (Geriatrics) Elder* (Elderly, Elders, etc.) Old* (Older, Oldest, etc.)
Intellectual/Developmental Disability	Disab* (Disability, Disabled, Disabling, etc.) Intellectual Disab* Developmental Disab*
Families	Famil* (Families, Family, Familial, etc.) Parent* (Parenting, Parents, Parented, etc.) Child* (Children, Childlike, etc.) Sib* (Sibling, Siblings, etc.) Grandparent* (Grandparents, Grandparenting, etc.)
Thriving	Thriv* (Thrive, Thriving, Thrived, etc.) Resilience Quality of Life Well-Being Flourish Self-Actualization Self-Determination Happiness

Search Methodology

Searches were completed using keyword search terms based on the four concepts. The first concept was “aging” which included the synonyms “Geriatric” “Elder” and “Old.” The second concept was “family” which included synonyms such as “Parent,” “Child,” and “Sibling.” The third concept was “disability” which included synonyms such as “Developmental Disability” and “Intellectual Disability.” The fourth and final concept was “thriving” which included synonyms such as “Resilience,” “Quality of Life,” “Well-being,” “Flourish,” “Self-Actualization,” “Self-Determination,” and “Happiness.” Additionally, we ensured that all the searches included the branches of the synonym terms. For example, a branch of “Old” would be “Older,” and a branch of “Family” would be “Families.” All synonyms and branches of those synonyms are listed in Appendix B.

All searches were limited to articles in English and published from 2000 onward. Searches also did not include any published book chapters because it was beyond the scope of this environmental scan. Searches did not include any dissertations, because they largely cite the research articles already extracted during the scan process. Searches did not include any articles that were not accessible via the University of Illinois at Chicago library system, unless those articles were openly accessible via Google Scholar. Articles that mentioned the COVID-19 virus within their title were not extracted for the scan due to the pandemic being an ongoing crisis event and potentially acting as a confounding variable upon ability to thrive (e.g., socioeconomic impact, vaccine access, decreased social interaction), thereby interfering with the understanding of factors affecting “thriving.” Originally, the synonym “Mental Retardation” was considered to be included as the concept of “Disability,” but the term was removed due to the frequency of duplicated results, and the term frequently being associated with older (prior to 2000) research.

All searches were limited to either the first three pages of results, or the first hundred individual results, whichever occurred first. Articles that were found to be duplicates from previous searches were not included in the final article count. Each search term resulted in approximately 0 to 100 articles, dependent on the term. Some search terms, such as “Flourish Intellectual Disab* Old*” had 0 results, while another term, “Self-Determination Disab*” had 47 results. A total number of 247 terms were searched across each of the five separate databases (Resulting in 1,235 total searches). A total of 2,562 articles were found. There were a total of 1,138 duplicates. After deleting duplicates, we ended up with a total of 1,424 articles to review. Out of those articles, 407 were determined to not fit into any of the study’s main themes, thereby reducing the total to 1,017 articles. As a result of the searches, we reviewed 1,107 abstracts, reducing the total articles to 323 using exclusion criteria (see Table 2). After applying another set of exclusion criteria, which included articles outside the United States, those with participants under 18, those which did not include IDD, and all theory or meta-

analysis articles, additional articles were removed, and we were left with a total of 76 peer-reviewed articles for full article peer review (see Appendix C). We included 14 additional articles from the grey literature.

Table 2. Literature Review Inclusion and Exclusion Criteria

Higher priority	Lower priority or excluded
Study target audience characteristics related to aging caregivers of people with IDD around thriving and well-being	Search results that were newspaper articles or book chapters were excluded due to abstract scanning being a central piece of methodology.
Describe interventions for aging caregivers thriving and well-being	Dissertation results were excluded due to most dissertation citations being articles that were found elsewhere in the scan.
Experience/perspectives and unmet needs of aging families (& families of people with IDD) on what helps them thrive	Any articles prior to 2000 were excluded as they were deemed lower priority for understanding the current family aging experience.
Resources/facilitators and barriers to access resources for aging families and people with IDD	The search term of Mental Retardation was excluded due to older terminology not being representative of the current family experience.
Focus on umbrella term of intellectual and developmental disabilities.	Search results that were not accessible in the home library of the researchers were excluded.
Use qualitative and quantitative research methods, including literature reviews	Any results related to COVID-19 were excluded due to the unique nature of the virus and the influence it had on “thriving” related research.
Describe theories related to thriving and family caregiving (for people with IDD)	A variety of other additional search terms were not included in the final search strategy due to the overarching nature of the environmental scan (Down syndrome, Learning Disab*, Grandmother, Brother, etc.).
	Any articles set outside of the United States were excluded
	Any articles whose primary participants were children with IDD under the age of 18 or their caregivers were excluded
	Any articles whose primary participants were people with disabilities other than IDD (chronic illness, mental illness, etc.) were excluded
	All articles which were theory only or meta-analysis/systematic review were excluded

Data Abstraction and Analysis

The final 76 peer-reviewed extracted articles were more carefully reviewed. Additionally, 14 grey literature articles were included which encompassed research briefs, resource sheets, and reports. Some of these grey literature articles were incorporated based on recommendations from the Florida Aging Caregiver Task Force regarding topics that were important. For example, Aging Generations' Expectations in Developmental Disabilities (AGEDD) project was reviewed. The project notes were reviewed as well. Each individual item was thoroughly reviewed and summarized by the research team. With the recent developments and emergence of generative artificial intelligence (AI), we tested the use of ChatGPT 3.5 to assist in the summarization of articles. The research team members summarized an article individually and then compared it to the summary produced by ChatGPT for that specific article and found that the summaries were comparable. However, a major difference was that the use of ChatGPT reduced the time for summarization significantly. Each generated summary was reviewed, and codes were developed. In a second review of the articles and the codes, themes emerged and fell under two main categories: (1) Support needs for aging families of people with IDD, and (2) Resources and supports that help people with IDD and their families thrive.

Findings

Support Needs and Barriers/Challenges for Families of People With IDD

Support Needs for Caregiver Role

The complicated and often all-consuming role of caregiver leads to family members of people with IDD needing more supports. Because caregivers provide complex care to their family members with IDD for long periods of time, they face many challenges on a day-to-day basis. The daily challenges and unpredictability associated with complex caregiving tasks make it difficult for families to thrive. A study by Wong and Shobo (2017) showed that parents of adults with DD have the longest caregiving role compared to other types of caregivers (such as adult children caring for aging parents or spouses caring for a partner with health conditions), often from the birth of their child and well into their old age. The longevity of the caregiving experience for parents of individuals with DD showed to have physical and psychological impact (Wong & Shobo, 2017). One of the challenges that adds to the complexity of caregiving is, according to Milliken and colleagues (2019), a “constant need to be on and managing multiple moving parts” (Milliken et al., 2019, p. 157).

Stress, Mental Health, and Coping Mechanisms

A study that examined the daily experiences of different types of caregivers found that parents caring for individuals with DD experienced more daily stressors compared to adults caring for aging parents or spouses with health conditions (Wong & Shobo, 2017). Unmarried/single parents of an individual with DD reported experiencing significantly greater stress than the other types of caregivers. The lack of a formal partner to help with the caregiving role seemed to exacerbate the stress experienced by the family caregiver.

A study that compared caregiver burden between caregivers of people with long-term care needs and those with DD found that caregivers of individuals with DD experience higher feelings of guilt related to their role (Pattison et al., 2021). Additionally, the highest stressor for caregivers in the study was role strain, which is the overwhelming feeling because of their caregiving role, and as a result were not able to effectively perform the role.

Through a national survey of 344 parents of adults with IDD, Burke and colleagues (2020) examined the experiences of family caregivers (Burke et al., 2020). They found that parents of adults with IDD spent a significant amount of their time providing caregiving tasks: over 25% of respondents spent over 60 hours a week on

caregiving and over 55% of respondents provided over 15 hours weekly of caregiving tasks (Burke et al., 2020).

Also, there is a correlation between the amount of stress parents experience, the amount of time they provide caregiving, and the maladaptive behaviors of the individual with IDD (Burke et al., 2020; Lee et al., 2019a). Adults with IDD who have greater support needs, including behavioral support needs, often require more caregiving support from parents. It is unclear if the support needs of the individual with IDD leads to more stress for parents which in turn leads to increased amounts of caregiving or, if the reverse is true and the support needs lead to greater time doing caregiving roles which leads to greater stress. It could be bi-directional, though more research is needed to examine this further (Burke et al., 2020).

The study by Perkins and Haley (2013) also showed that caregivers experiencing the relative disadvantage in reciprocity were less likely to look for alternative residential placement, possibly because of “a perceived sense of role captivity” (p. 341) as a lifelong caregiver. Relative disadvantage in reciprocity refers to “a negative imbalance in the exchange of duties within the caregiving relationship,” indicating that the individual receiving care has higher needs for support and/or lack of ability to give support (Perkins & Haley, 2013, p. 340).

Contrary to stereotypical views, both mothers and fathers of individuals with IDD experience increased stress, emphasizing shared experiences rather than gender-related differences (Ha et al., 2008). However, mothers perceived greater burden related to their caregiving role compared to fathers. Yet, mothers may experience lower psychological distress and enhanced well-being compared to fathers, possibly because of greater emotional gratification and satisfaction they glean from caregiving as well as greater access to informal social support than men (Ha et al., 2008; Homan et al., 2020). Mothers of adult children with IDD who are exhibiting socially maladaptive behaviors are more likely to experience high health-related stress in their own lives (Pruchno & Meeks, 2004). A survey study of 932 mothers revealed that those experiencing high stress also had lower positive affect scores and higher depressive symptomatology scores, suggesting that interventions aimed at increasing positive affect and reducing negative affect may be crucial for improving their lives (Pruchno & Meeks, 2004).

Coping mechanisms have been shown to influence caregiver well-being (Kim et al., 2003). While problem-focused coping (involving active planning and taking direct action to remove the stressor or reducing its effect) seemed to regulate the well-being of parents of adults with IDD, parents who engaged in emotion-focused coping to deal with the stressor (involving denial, focusing on and venting emotions,

reducing one's effort on other activities and/or distracting oneself from thinking about the stressor, and mental disengagement) experienced higher subjective burden, depression and a strained relationship with their adult child (Kim et al., 2003). It is important to note that coping mechanisms can be dynamic, and parents could change their ways of coping, even if they have been exposed to stressors for decades, thereby causing fluctuations in their well-being (Kim et al., 2003). It is important for practitioners and service providers to promote problem-focused coping strategies among caregivers by focusing on professionally led psychoeducational programs and encouraging caregivers to join informal support groups so that families can learn new problem-solving strategies and manage stressors related to caregiving (Kim et al., 2003).

Coping strategies among adult and adolescent siblings of people with IDD exhibit distinct patterns. Adult siblings tend to utilize more problem-focused coping and fewer emotion-focused coping strategies compared to their adolescent counterparts (Orsmond & Seltzer, 2009). While these differences align with typical age patterns, problem-focused coping proves to be more effective in protecting against the negative effects of behavior problems in siblings with Autism Spectrum Disorder (ASD) (Orsmond & Seltzer, 2009). This insight underscores the significance of considering age-appropriate coping mechanisms in supporting siblings throughout their lifespan.

Chronic Health Conditions

The presence of chronic health conditions, such as arthritis, asthma, diabetes, angina or coronary heart disease, heart attack, stroke, high blood pressure, high blood cholesterol, and/or osteoporosis, can limit caregivers' capacity to provide care on a day-to-day basis. Studies have shown that despite the physical health challenges, caregiving responsibilities do not change and it can be difficult for families to find alternative residential placement options for their family members with IDD (Seltzer et al., 2011; Yamaki et al., 2009). In one study, parent caregivers of adults with IDD exhibited poorer physical and mental health than the general population, with less than one-third reporting access to any mental health support (Santos et al., 2023).

Additionally, poor mental health and mental distress prevent caregivers from taking care of themselves as well as their family members with IDD. Poor mental health could be associated with the caregivers' declining physical health status combined with their worry about the future of their family member with IDD (Yamaki et al., 2009).

In a longitudinal study over a 20-year period, the experiences of parents of adults with and without disabilities were compared. Findings showed that parents of adults with disabilities experienced poorer health and well-being in their mid-60s and declined further in their early 70s, compared to parents of adults without disabilities. Parents that lived together with their adult child with disabilities had greater health symptoms, increased levels of depressive symptoms, greater body mass index (BMI), and less social visits with friends compared to parents that lived in separate residences from the individual with IDD (Namkung et al., 2018). This study points to the needs for greater supports and interventions targeted to aging parents of adults with IDD, especially 60 years and older where sharp declines in health occur.

Impact of Family Characteristics, Structure, and Dynamics

Family is an integrated and functional unit of society. Family characteristics, structure, and dynamics play an important role in how the development, behavior and functioning of an individual is impacted. Furthermore, the structure of a family affects caregiving dynamics and thereby, their well-being. Various factors, such as marital status, race, education, employment status, income, and the number of children, play roles in shaping the overall well-being of parents of individuals with IDD (Ha et al., 2008).

Interestingly, older parents of disabled children experience a less pronounced impact on well-being compared to younger parents (Ha et al., 2008). There is evidence that families in which there were younger parents or who had more than one child with a disability showed higher negative affect. On the contrary, White parents of children with IDD exhibited lower negative affect and significantly higher psychological well-being than parents of different races/ethnicities (Ha et al., 2008). Also, families with younger mothers at the time of birth had a higher risk for divorce (Bahri et al., 2023). Furthermore, when parents in their early old age coresided with their adult children with disabilities, they experienced more social isolation and greater depressive symptoms, which would take a toll on their psychological functioning (Olsen et al., 2018; Seltzer et al., 2011).

Emotional barriers in communication might prevent people from openly communicating their thoughts and feelings, leading to conflicts and disagreements. *Parental ambivalence*, referring to ambiguity of parents around how much care and support a person with a disability needs, and around expectations of how their other children without disabilities will be involved in future caregiving for their siblings with disabilities, might create disagreements between parents and their children without disabilities (Namkung et al., 2020). Conflicts also arise when nondisabled children experience resentment to their parents' inability to invest equally in their relationships with all of their children, resulting in feelings of resentment among

nondisabled children and producing conflict/tension in their relationships with their parents (Namkung et al., 2020). Aging parents' experience of ambivalence coupled with conflict with their nondisabled children have been shown to increase the caregivers' depressive symptoms and reduce their levels of life satisfaction and quality of life (Namkung et al., 2020). There is no agreed upon measure of quality of life and researchers have used both subjective and objective measures of well-being to explore the concept (Imbulana Arachchi, & Managi, 2023). Namkung and colleagues (2020), therefore, underscore the importance of including measures of parental ambivalence in future studies on health and well-being of caregivers of adults with IDD.

Social Support Needs

Social support is a vital need for individuals with and without disabilities. Social opportunities have a direct link to higher rates of happiness and independence for individuals with disabilities (Anderson et al., 2023; Davis et al., 2004). Social participation, a critical aspect of an individual's life involving interaction with others in the community and nurturing interpersonal relationships, influenced their psychological well-being. According to Olsen and colleagues (2018), having limited social participation, especially for older caregivers, increases their depressive symptomatology and decreases their access to crucial resources and support systems that are important for coping with stressors. In particular, parents face difficulties in addressing their child's immediate as well as long-term needs and care plans when they are unable to get support from their families (Olsen et al., 2018).

Impact from Relationship with Individuals with IDD

The dynamics of relationships between the caregivers and their family members with IDD affect the well-being of the caregivers. A semi-structured interview study by Perkins and Haley (2013) showed that when caregivers felt that they were giving much more in the relationship than they were getting, termed relative disadvantage in reciprocity, they experienced poorer mental health outcomes. Strained interpersonal relationships with a child with IDD can also impact parents' physical health (Namkung et al., 2018).

Perceptions of emotional reciprocity within parent-child relationships are crucial. Parents who perceive little emotional reciprocity experience higher depressive symptomatology scores and poorer global mental health (Perkins & Haley, 2013). Surprisingly, carers feeling a negative imbalance in emotional reciprocity are not more inclined to consider placing their care recipient into alternative residential care (Perkins & Haley, 2013).

Sibling Relationships

Specific to siblings of individuals with disabilities, family stress severity, potential shared genetic vulnerability and the nature of siblings' disability influence their cognitive functioning and psychological well-being (Wolfe et al., 2014). Siblings of adults with mild ID showed an obligatory relationship but exhibited lower emotional proximity (Taylor et al., 2008). Studies showed that the sibling relationship was negatively impacted by the behavior problems in their sibling with autism (Bahri et al., 2023; Orsmond & Seltzer, 2009). Typically developing siblings of individuals with ASD may be at a greater risk for depression, stress, and providing less aid/support than typically developing siblings of individuals with IDD due to lower positive sibling relationship attitudes (Tomeny et al., 2017).

Compound caregiving is when an individual caregiver has multiple caregiving responsibilities. For example, this can include siblings that care for aging parents, children, or their brother or sister with disabilities. A study of 332 adult siblings of adults with IDD (Lee et al., 2020) found the following barriers identified by sibling caregivers related to their caregiving role included the following *systemic barriers* such as lack of or low-quality services and support, difficulty navigating the system, long waiting lists, limited funding, lack of transportation options, and other related barriers:

- *lack of information* about the service system and how to navigate it;
- *family conflicts* such as difficulty communicating and lack of discussion about family future planning,
- *lack of supports for siblings* of individuals with IDD such as peer support groups with other siblings;
- *siblings struggling to balance life with caregiving*, especially while juggling multiple caregiving roles;
- *limited public awareness of the importance of the role and experience of siblings* of people with IDD; and
- *no barriers* which were mostly reported by siblings who were not currently in a caregiving role.

It is interesting to note that caregivers involved with compound caregiving experience reduction in social network/support, difficulty in prioritizing caregiving demands, and a reduction in stress resiliency, thereby impacting their overall well-being (Perkins, 2010). While parents express stress related to support and service needs, typically developing siblings report more stress in interpersonal and family dynamics (Lee et al., 2019a).

Support Needs Related to Services

Family caregivers need support related to the services for the individual with IDD. This included navigating the support system, finding available support that matched

the needs of the person with IDD, as well as getting information so that they can support the individual with IDD. Bureaucratic/administrative hurdles and difficulty navigating paperwork add to the already existing challenges (Milliken et al., 2019).

Finding available supports for adults with IDD is challenging. A study that examined 366 caregivers of adults with IDD, dementia or other conditions, found a mismatch between the needs of caregivers of adults with IDD and the amount of services they utilized. Some possible reasons for lack of service utilization for caregivers of adults with IDD include the unavailability of services that are needed and difficulty navigating the system in order to access services (Fleming & Litzelman, 2021). While participant directed programs are meant to be tailored to the needs of the individual, caregivers have often identified gaps in these programs when there is a misalignment between the needs of the person and the supports provided. For example, some interventions that are standardized are not always useful for specific care recipients' and their families. Flexibility should be infused into interventions so that they can be effectively adapted for the unique needs of various people (Milliken et al., 2019). Additionally, flexibility in funding for community-based supports is needed to promote post-retirement activities beyond center-based programs (Anderson et al., 2023).

Families encounter barriers to accessing services, including a lack of awareness of available services and long waits for the services they are aware of (Marsack-Topolewski et al., 2023). These challenges emphasize the need for improved accessibility and awareness of support services for families of individuals with IDD. There is a need for tailored services and programs to address the daily challenges faced by family caregivers in midlife and late adulthood, especially those caring for individuals with DD (Anderson et al., 2023; Milliken et al., 2019). Also, there is a need for services and supports tailored to the unique needs of family caregivers of adults with IDD to help with their caregiving role, especially to help reduce demands and stress and increase health and well-being (Wong & Shobo, 2017).

Navigating Services

Navigating service systems and accessing quality programs for adults with IDD are reported as significant challenges by families, as highlighted by Lee et al (2019). For example, this could include there is a dearth of transition activities when moving from the pediatric to adult health systems. Also, there is lack of support for linguistic and culturally diverse populations. Additionally, there could be lack of funding for updating service systems, resulting in outdated websites or programs. On the other hand, having financial supports could circumvent the long waiting lists most families are on for years before receiving their needed services. This underscores the importance of enhancing the accessibility and quality of programs available to this

population. By addressing these challenges, service providers can contribute to a more seamless and supportive experience for families of individuals with IDD. Systemic issues, such as high turnover rates among support workers, may provide additional challenges. This highlights the critical need for service agencies catering to adults with IDD to establish individually tailored and responsive support systems. These systems should align with the principles of person- and family-centered care (Milliken et al., 2019). Person- and family-centered care focuses the wants and needs of the individual and the family unit respectively, while designing programs or interventions (Anderson et al., 2023; Thalen et al., 2023). Recognizing and addressing these challenges is essential in ensuring that the support provided is not only effective but also sustainable.

Information Support Needs

There is a huge need for information support for family members of adults with IDD such as education and training on various topics. For example, family members wanted information about residential, vocational, and postsecondary settings (Gilson et al., 2017), retirement planning (Anderson et al., 2023), sexual health (Kammes et al., 2020), and more. Family members of individuals with IDD underscored the importance of gaining comprehensive information on the health trajectory of their loved ones, including insights into age-related changes .

Siblings of individuals with IDD have specified they have needs for information about the formal support system and to help navigate the disability system as they take on greater caregiving roles (Arnold et al., 2012). The most requested informational need for siblings was how to connect with other siblings for peer support. Additionally, information was needed about planning for the future, including information on legal and financial planning, guardianship transitions, and estate planning (Arnold et al., 2012). Resources or supports given to individuals with IDD should also be shared or discussed with siblings, as that connection and education can strengthen sibling relationships (Rossetti et al., 2020).

Financial Support Needs

Parents of individuals with disabilities are likely to have less in savings and income compared to their peers who do not have children with disabilities (Parish et al., 2004). The financial assistance opportunities offered to families are essential to survive, and financial assistance for families of individuals with disabilities should be improved to help foster environments where families can thrive.

Aging parents of children with IDD are financially vulnerable, particularly in the context of retirement. The decline in net worth for retirement-aged parents indicates

potential challenges in financing both their own retirements and the ongoing care needs of their adult children with disabilities (Parish et al., 2010).

Studies showed that time commitments for caregiving reduced employment opportunities and had a fiscal cost (Burke et al., 2020; Parish et al., 2004). One study found that parental employment status and education level predicted their well-being. Parents who were employed and thereby took a break from caregiving tasks and engaged in other activities showed lower negative affect, and experienced less distress and higher psychological well-being (Ha et al., 2008). Educated parents could possibly experience less stress because they could access more services (Bahri et al., 2023). Financial instability, particularly in terms of asset poverty and low liquid assets, has implications for the psychosocial well-being of both parents and their children with IDD (Parish et al., 2010).

Support Needs for Transitions of Care

As individuals with IDD live longer, they are increasingly outliving their parents and transitions of care have become more necessary, often to siblings within the family (Burke et al., 2020). In addition, caregivers themselves undergo transitions because of aging and physical challenges, leading to fears about the future regarding their family members with IDD. Furthermore, it has been shown that the transition planning process and the worry about how to make their children independent leads to marital conflicts (Bahri et al., 2023).

Caregiving is complex and has both benefits and challenges. Transitions of care are especially challenging. Care transitions occur at expected lifestages as well as unexpected times in life due to certain circumstances. Regardless of whether the transition was expected or unexpected, it is still difficult. Additionally, parents experience fear related to the impact on their caregiving capabilities as they age (Milliken et al., 2019). The future caregiving roles are of great concern related to adults with IDD. In a national survey of 344 parents of adults with IDD, 37.72% of parents expected their other children, the siblings, to fulfill the caregiving role; 38.58% of parents did not know who would be the future caregiver; 10.23% responded they had no one for this role; and 10.23% indicated they anticipated the state would be the one to care for the loved one when they could no longer do so (Burke et al., 2020).

Another study surveyed 108 young adult siblings (ages 18–25 years) of individuals with disabilities (Nuttall et al., 2018). This study found that siblings were more likely to report intentions for providing caregiving for their sibling with Down syndrome while reporting less intention for taking on a caregiving role if they had a sibling with ASD. Siblings took on caregiving roles during their childhood where they provided

support and care for their sibling with disabilities (i.e., sibling-focused parentification) as well as provided support to their parents to help them cope with having a child with disabilities (i.e., parent-focused parentification). An unexpected finding was that siblings who provided more parent-focused participation to support their parents when they were growing up were less likely to see benefits to the caregiving role and had less intention of taking on caregiving roles in the future for their brother or sister with disabilities.

Common challenges experienced within families included the ambiguity about the future, communication issues among family members, disparate views among family members, and a struggle for siblings to juggle caregiving roles within their lives (Lee et al., 2019b). Family caregivers of aging adults with IDD face mental health challenges as they navigate the increased support needs of the person with IDD alongside other responsibilities (Sullivan et al., 2019). Sullivan et al. (2019) emphasized the importance of considering the changing needs of both individuals with IDD and their caregivers. Proactively addressing these transitions ensures a more seamless and effective support system that adapts to the evolving requirements of this population.

Healthcare Transitions

The transition from pediatric healthcare systems to adult healthcare systems poses a unique set of challenges for individuals with IDD and their families. In focus groups, family members expressed concerns about the differences in receiving information about care options, and accessing that healthcare, between the two systems. One family member captured this sentiment, stating, "As a child, everyone would fight to give the best care; now at 23 years, you need to prove his worth to get services" (Krahn et al., 2023, p. 316). As individuals with IDD age, and as their support needs evolve, the development and facilitation of transition plans from adult to aging service systems may also provide additional challenges. Some of these challenges could be education on available resources, and the accessibility or availability of those resources.

Planning for Future/Long-Term Care Planning

Families tend to provide extensive at-home support systems for their family member with IDD. However, as the parents and children both age, they may come to rely more on formal support systems. Disability policies must consider the caregiving capacity of families, particularly as the population ages (Fujiura, 2010). Parents of adult children with "serious conditions" (which included both physical disability and IDD) are at increased risk for poorer physical health themselves (Cha & Crosnoe, 2022). The longer a parent continues to provide care to a child with a serious health condition, the stronger the negative impact on their own physical health. This

emphasizes a need for sustained care and support for these parents (Cha & Crosnoe, 2022).

A 2009 study revealed that a significant proportion of adults with disabilities live in households where the primary income earner is 60 years or older, suggesting increased demands on support systems as the population ages. This prompts consideration of future policy measures to address potential challenges in providing long-term care (Fujiura, 2010).

As parents of adults with IDD experience an increase in functional limitations due to aging, their reliance on the social participation of their typically developing adult children becomes pivotal. Olsen et al. (2018) noted that not having any typically developing children may impede parents' ability to meet the immediate needs of their children with IDD. The evolving dynamics within these families underscore the importance of understanding and addressing the unique challenges that arise as both parents and their adult children age (Olsen et al., 2018).

Siblings often take on greater support and caregiving roles as parents age. Most siblings anticipate some level of involvement in the future care and support of their brother or sister with DD (Heller & Arnold, 2010). A qualitative study interviewed 10 parent-sibling dyads of people with IDD about long-term planning (Lee et al., 2019b). While most of the parent-sibling dyads had discussed future planning, the conversations tended to be vague and lack specificity, which left a lot of areas in need of discussion and without specific plans. Also, as part of the future planning conversations, there were often points of disagreement that families had to work through. Future planning was a stressful process for most families. Common stressors included competing pressures within families, capabilities of the person with IDD, lack of quality residential and employment options, and financial concerns. While parents were most stressed about obtaining supports and services, siblings were most concerned about the family dynamics (Lee et al., 2019b).

Barriers to future planning for individuals with IDD and their families encompass a spectrum of challenges. These obstacles range from seemingly small issues such as procrastination and disagreements between family members to more complex issues like a lack of access to day programs. Heller and Caldwell (2006) emphasized the emotional challenges that arise from facing mortality and navigating systems designed to provide essential services (Heller & Caldwell, 2006). Recognizing and addressing these multifaceted barriers is crucial in developing comprehensive and effective future planning strategies for individuals with IDD and their families.

Resources and Supports That Help People With IDD and Their Families Thrive

Families: Resources and Supports

Social Supports for Families

Social connections play a vital role in the well-being of aging parents living with their adult children with IDD. Engaging in social activities, such as socializing with friends and family and participating in social organizations, have been identified as a protective factor against depression in this demographic (Olsen et al., 2018). Additionally, parents who have other children besides the one with IDD find these relationships to be a crucial support system, aiding in addressing the day-to-day needs of adult children living at home (Olsen et al., 2018).

Sibling Support

Strong social bonds within the family of people with IDD, particularly between siblings, play a significant role in caregiving responsibilities. When siblings are involved in caregiving for their sibling with IDD, it strengthens sibling relationship quality, advocacy, and level of future planning (Lee et al., 2019b). Furthermore, parents' relationships with their typically developing adult children significantly impact their own health and well-being, making them better able to provide care for their children with IDD. Parents who support their typically developing adult children in finding jobs, getting an education, and getting married have reduced conflict and better physical and mental health (Namkung et al., 2018). In a survey study of typically developing siblings of adults with autism or IDD, positive sibling relationship attitudes were associated with higher life satisfaction and lower depression and stress levels in these siblings (Tomeny et al., 2017).

A survey involving 796 adult siblings of individuals with IDD revealed that the absence of daytime activities was associated with negative outcomes for their adult siblings, such as depressive symptoms, ill health, and less-than-optimal relationships. This underscores the potential role of natural supports, particularly siblings, in providing instrumental and emotional assistance to individuals with IDD (Taylor & Hodapp, 2012) and highlights that siblings will need support themselves for these roles. Additionally, inadequate systems of adult care for adults with IDD may lead to increased caregiving responsibilities for siblings when parents can no longer provide care (Taylor & Hodapp, 2012). Comparing siblings of adults with mental illness and siblings of adults with mild IDD, the latter were more likely to live in the same state, indicating some social support through proximity. However, they were also less likely to report emotional closeness, suggesting that the social support might be more obligatory than emotionally fulfilling (Taylor et al., 2008). Siblings of adults with mild IDD visited their sibling more frequently than siblings of

people with mental illness but were also less likely to report being able to talk with siblings (Taylor et al., 2008).

Grandparent Support

One study examined the ways grandparents of individuals with ID provide support to mothers of the person with ID (Heller et al., 2000, p. 2) . The study, including grandparents who were parents and in-laws of 120 mothers of individuals with ID, found that grandparents provided important instrumental support to mothers when the individual with IDD was a child and this type of support lessened as the individual grew up. Some examples of instrumental support included taking care of the child, doing household chores, helping find services, and providing financial assistance. Grandparents also provided important emotional support which stayed consistent at various ages. Emotional support provided by grandparents was associated with less depression in mothers. Yet, grandparents of children with intellectual disabilities want more support themselves but rarely receive this from professionals (Heller et al., 2000).

Leisure Activities

A study comparing different types of caregivers found that although unmarried/single parents of adults with DD had the most stress, they also spent more of their time on leisure activities (defined as actively choosing to do things for themselves) compared to the other types of caregivers. This could indicate that leisure activities is a critical coping strategy for these family caregivers, which is in line with previous research showing how leisure activities can help with coping (Nimrod et al., 2012) and serve as moderators and mediators of psychological well-being (Zawadzki et al., 2015). When single parents do not have a partner to turn to for support, they may find leisure activities help them manage the stress they are experiencing as family caregivers.

Peer Navigators

According to a study with aging caregivers of adults with IDD, working with peer navigators or mentors was found to reduce perceived barriers to using and needing formal supports and services (Marsack-Topolewski et al., 2023). The peer support program helped participants learn how to navigate existing resources for aging families and people with IDD, and helped individuals learn how to advocate for what they needed. This peer navigator program could serve as a model for more programs where aging family caregivers can learn from each other and support each other.

Health & Psychosocial Health Supports for Families

Family caregivers have better health and psychosocial health outcomes when they receive supports targeted to their needs. Without adequate training, support, and respite, family caregivers have negative outcomes to their health and well-being. To support caregivers, health care systems need to identify ways that the health needs of family caregivers can be incorporated into existing systems. The 2022 National Strategy to Support Family Caregivers recommends that the healthcare systems “can identify opportunities to include family caregivers and care recipients on decision-making boards and incorporate family caregiver awareness into training protocols and patient education materials” (Administration for Community Living, 2022).

Psychosocial support programs can reduce caregiver burden and improve their mental health and well-being. Psychosocial programs include support and counseling as well as education and training for caregivers. This can include support groups, specific education related to disease-specific education, counseling sessions, and more (Heller et al., 2017). Another study found that parents who, over the years, managed to adjust their dreams and goals (self-actualization) and find meaning in their caregiving role expressed satisfaction with their life (Avieli et al., 2022).

Mindfulness

Mindfulness-Based Stress Reduction (MBSR) emerged as a positive intervention for parents of individuals with IDD, contributing to stress reduction, improved self-compassion, and enhanced psychological well-being (Bazzano et al., 2015). MBSR equips parent caregivers with strategies to manage stress, focus on the present, accept current situations, and increase tolerance of uncertainty. These coping skills contribute to building resilience and improving parent-child relationships (Bazzano et al., 2015).

Mother's Impact on Children

Parental mental health impacts adult children with disabilities significantly (Esbensen et al., 2013). Mothers' mental health plays a role in behaviors of their adult children with Down syndrome, such that adults with Down syndrome are less likely to have behavioral issues if their parent has less “depressive symptoms” (Esbensen et al., 2013, p.). Maternal optimism plays a role in the well-being of both mothers and their children with disabilities. Maternal well-being is also impacted by the relationship strength between mothers and their children with disabilities (Greenberg et al., 2004). Interventions that focus on honing optimism as a psychological and social resource for family caregivers hold promise for improving family relationships and improving health and well-being for parents and people with disabilities.

Most chronic conditions are preventable and manageable, and therefore health promotion programs targeting chronic disease prevention and management should be prioritized (Krahn et al., 2023). Furthermore, mental health of the caregivers should not be neglected. Stakeholder focus groups, including people with IDD, family members, and professionals, highlight the need for increased attention to mental health for individuals with IDD, addressing consequences such as violence or trauma in their lives (Krahn et al., 2023). Caregivers experiencing poor mental health should be encouraged to access formal resources such as crisis prevention and counseling/mental health services, and informal resources such as peer support groups.

Instrumental Supports for Families

Instrumental supports include both informal and formal supports that help people with IDD thrive. Instrumental support includes concrete and direct ways people assist others such as through material goods or services. It can also include physical help with tasks for daily living, medical and health supports, and assistance with navigating services, (Langford et al., 1997) as well as financial assistance (Tardy, 1985).

Formal Supports

Most adults with IDD and some caregivers are Medicaid-eligible, or dually eligible for Medicare and Medicaid. It is important to consider the Home- and Community-Based Services (HCBS) needs of both adults with IDD and their caregivers. By applying person-centered planning and practices, states can provide culturally and linguistically competent supports. Principles such as focusing on the person, choice and self-determination, community inclusion, access to individualized services have been useful for person-centered practices (Centers for Medicaid & Medicare Services, 2023). In a comprehensive study involving 405 caregivers of individuals with IDD, various formal system supports were identified, including federal health insurance (61.7%), monthly cash stipends (58.8%), and Medicaid waivers (47.4%). These formal supports played a vital role in the well-being of parents, emphasizing the ongoing need for their expansion (Santos et al., 2023). Formal supports, especially those involving future planning are crucial, and the earlier they can be accessed by families, the better (Anderson et al., 2023). Additionally, respite care is essential, yet underutilized by families (Xu et al., 2022).

Self-Directed Supports

Designing and tailoring supports and interventions for caregivers can be achieved only by understanding aspects of complexity. Milliken and colleagues (2019) described participant-directed programs that helped caregivers choose services that

best met their needs and allowed flexibility, as one of the most effective ways to promote their independence and to consequently thrive. Participant-directed programs have been found to benefit both caregivers and those receiving care, where participants (those who receive care) are provided with the budget and time to develop their own program plans. An example of this is deciding a day program's schedule based on the wants of those attending the day program. In addition, the authors reinforced the importance of informal networks of support for an opportunity to connect with someone going through similar experiences.

Support Brokers

Family caregivers of adults with IDD experience enhanced well-being when formal support programs incorporate flexibility, control, and participant direction for their children (Milliken et al., 2019). The presence of a highly involved "support broker," often a knowledgeable social worker, significantly contributes to positive experiences for caregivers by providing information, creativity, and a rapid response to their needs (Milliken et al., 2019, p.). Support brokers can help when primary caregivers are no longer able to provide self-directed supports, such as filling the role of the caregiver or finding someone to replace the caregiver (Thompson & Young, 2023). Support brokers can help by providing guidance so the individual can direct their own services and serves as a liaison between the individual and program (Medicaid.gov, 2023).

Support Provided by Individuals With IDD

Both emotional and tangible reciprocity exist in relationships between caregivers and their adult sons/daughters with intellectual disabilities. Tangible reciprocity, such as help with household tasks, helps contribute to improved relationships between the parent and the adult with IDD (Perkins & Haley, 2013). The perceived imbalance in the exchange of tangible and emotional support within the caregiving relationship is linked to negative mental health outcomes for the caregiver (Perkins & Haley, 2013).

One study examined the experiences of 305 unmarried older (i.e., aged 50-91 years) mothers who lived with their adult child with DD. While mothers provide a great deal of caregiving support to their adult child with DD, this study found that the individual with DD also provides important support to their mothers, especially as they age. Mothers tended to provide a significant amount of functional assistance such as with managing money, going to the grocery store and meal prep, laundry, and more (Pruchno, 2003). Additionally, unmarried caregivers, lacking support systems, may benefit from initiatives to reduce caregiving demands (Anderson et al., 2023).

Mothers reported that the individuals with IDD also provided functional assistance to them by helping with housework, meal preparation, and grocery shopping.

Additionally, the emotional support that adults with DD provided to their mothers, through showing affection and keeping them company, was correlated with an increase in caregiver satisfaction of the mothers (Pruchno, 2003). Therefore, there is a need for support models and interventions that are developed to provide increased assistance to both parents as well as for adults with IDD, especially as they both get older and their support needs increase (Pruchno, 2003). Those models and interventions could focus on larger needs (e.g., financial planning, after-death care) or smaller day-to-day practices and needs (e.g., doing laundry, grocery shopping).

Coordinated Healthcare

The enrollment of adults with IDD in coordinated government healthcare systems, such as the Veteran's Administration, appears to alleviate challenges related to payment and healthcare coordination (Fresher-Samways et al., 2003). Those enrolled in such programs experienced fewer challenges compared to their counterparts who are not part of coordinated government healthcare systems (Fresher-Samways et al., 2003). This finding underscores the potential benefits of integrating individuals with IDD into coordinated healthcare systems.

Counseling and Peer Support Groups

For the caregivers experiencing social isolation, formal supports such as counseling and informal supports such as support groups might help the caregivers to make connections with families, friends and other community members. In a review of social support interventions, Hogan and colleagues (2002) found that support provided by peers, especially family and friends, seemed especially effective. There are a number of support groups available to caregivers, such as Caregivers Connect, Working Daughter, Alzheimer's and Dementia Caregiving Center, and Sibling Leadership Network (National Association of County and City Health Officials, 2023).

Future Planning Supports for Families

In the words of Heller and Caldwell (Heller & Caldwell, 2006), "planning for the future is a complex, dynamic, and emotional process for families with relatives who have developmental disabilities" (p. 196). Addressing the emotionally difficult and sensitive topic of long-term care planning (LTCP) for adults with IDD is significantly facilitated by having strong social supports. Caregivers with identified social support not only show further progression in LTCP but also experience lower caregiver burden (Santos et al., 2023). Peer support plays a significant role in future planning success, allowing aging caregivers and individuals with IDD to gain the perspective and wisdom needed to make the right choices for their families (Heller & Caldwell, 2006).

Siblings frequently take over caregiving for their family member with IDD from their parents, and are more likely to transition into a caregiving role successfully with the help of future planning (Coyle et al., 2014). Sibling caregiver success is due to a variety of factors such as the adjustment period to being a main caregiver, the age of both the individual requiring care and the caregiver, the amount of future planning undertaken, and the available resources (Coyle et al., 2014).

A survey of mothers of adults with IDD revealed that ongoing caregiving stressors, compounded by major life events related to health, can contribute to affective distress. This emphasizes the need for sustained support for caregivers over time, especially when considering the long-term implications of caregiving (Pruchno & Meeks, 2004). Individuals with IDD who have involved siblings are more likely to engage in future planning, emphasizing the role of familial relationships in shaping long-term care considerations (Lee et al., 2019b). Future planning interventions should consider the attitudes of typically developing siblings of people with IDD and ASD, as their perspectives play a crucial role in shaping the future plans for their siblings (Tomeny et al., 2017).

Family caregivers of people with IDD encounter significant challenges in making future arrangements for their children. Many families, unaware of available housing options, often consider residential care as the only choice. Additionally, reluctance to involve typically developing children in caregiving or consider their input into future planning for the child with IDD is common. Proactive support from social services may facilitate this planning (Gilbert et al., 2008). Practitioners can also play a crucial role in facilitating family communication and offering support for families regarding future planning. For individuals with IDD to thrive, long-term planning should involve specific and definitive plans. However, stressful family dynamics, especially between parents and typically developing adult siblings, may hinder this process (Lee et al., 2019). Transitioning from more restrictive settings to community-based environments that prioritize autonomy and self-determination leads to more positive outcomes for people with IDD. Providing adequate supports and accommodations are crucial to enable individuals to move to non-congregate settings for long-term care (Wehmeyer & Bolding, 2001).

Most caregivers take on an advocacy role at some point to help improve systems of support and ensure their loved ones receives the resources they need (Milliken et al., 2019). A study by Caldwell and colleagues (2018) shows that advocacy and empowerment could improve overall positive family adaptation by mechanisms such as influencing environments and gaining control over their lives in a positive way.

The Future is Now is an evidence-informed curriculum that uses a peer support model which incorporates people with DD and families to be co-facilitators in the training (Factor et al., 2010). This intervention has shown success in helping families make plans, including completing a letter of intent, taking action on residential planning, and creating a special needs trust. Positive outcomes of this intervention included a decrease in caregiver burden as well as increased opportunities for the person with DD to participate in choice-making (Heller & Caldwell, 2006). A virtual version of the curriculum has been developed to reach more families across the country (Arnold et al., 2023). Also, the Arc's Center on Future Planning was created to support and encourage adults with IDD and their families to plan for the future. The Center provides reliable information and assistance to individuals with IDD, their family members and friends, professionals who support them and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning. There is an online tool that helps families build a plan for the future that can be saved and shared among family members (<https://futureplanning.thearc.org/>).

Technological Supports

Remote technology supports such as motion sensing systems, radio frequency identification, live audio feeds, web-based monitoring systems, or the application of devices that facilitate two-way communication, have been shown to be effective in improving communications between providers and the caregivers and their family member with IDD and access to various other supports. Remote technology supports are not useful if the caregiver has low digital literacy. Digital literacy of caregivers could be improved through various training programs such as statewide Technology Act programs (Tanis & ANCOR, 2019). Technology First began as a movement but has transformed into a "framework for systems change where technology is considered first in the discussion of support options available to individuals and families through person-directed approaches to promote meaningful participation, social inclusion, self-determination, and quality of life" (Tanis, 2019).

Technology has been used more in the aging field to deliver interventions from a distance using videos, the telephone, and the internet. The use of technology has benefits such as being able to reach people who are low-income and in rural areas who are traditionally underserved (Heller et al., 2015). Another study explored innovative approaches, focused on the feasibility, acceptability, and usefulness of a novel program using a social robot to provide respite care for older family caregivers of young adults with IDD. The social robot provided companionship and friendship to young adults with IDD, offering them a social interaction that caregivers might not always provide. Caregivers expressed positive feedback regarding the potential

benefits of the robot, suggesting it could provide physical and emotional respite for them (Xu et al., 2022).

Individuals with IDD: Resources and Supports

Social Supports for People With IDD

Having adequate social supports is crucial for people with IDD for the promotion of well-being, independence, emotional and practical support, and quality of life. The ability of individuals with IDD to choose their services can enhance natural and instrumental supports by aligning the services with their individual needs and preferences (Friedman & VanPuymbrouck, 2019).

Natural Supports

Examining natural supports, a study of 7,118 people with IDD found that approximately 41.0% of adults with disabilities were connected to natural support networks, while 59.0% were not (Friedman, 2023). Natural support networks significantly impact the quality of life for adults with IDD, influencing personal goals, work choices, living environments, and freedom from abuse. However, disparities exist, with women with disabilities and Black individuals with disabilities being less likely to be connected to natural support networks. In contrast, autistic individuals, those with Down syndrome, and those living in family homes were more likely to have natural support networks (Friedman, 2023). The odds of having friends increased by 241%, and the odds of participating in the life of the community increased by 243% when individuals with IDD had natural support networks (Friedman, 2023).

Family Supports

The impact of family characteristics on sibling relationships and relationships between individuals with IDD and their typically developing siblings plays a crucial role in providing instrumental aid and support. Siblings with positive relationships were more likely to offer instrumental supports to individuals with IDD, emphasizing the importance of familial bonds in enhancing the well-being of individuals with disabilities (Tomeny et al., 2017). Drawing a comparison between adolescent and adult siblings of people with IDD, Orsmond and Seltzer (2009) discovered that adolescent siblings perceived greater support from parents and friends in contrast to their adult counterparts. This parental support was associated with positive affect in the sibling relationship, emphasizing the enduring influence of family dynamics on the well-being of individuals with IDD and their typically developing siblings. Moreover, the role of parental support and coping strategies emerges as essential in maintaining positive relationships into adulthood for typically developing siblings (Orsmond & Seltzer, 2009).

Formal Supports

Regarding formal supports, enrollment in formal services was found to predict the presence or absence of daytime activities for people with IDD. Formal supports could range from financial or governmental assistance (e.g., Medicaid waiver, food stamps) to meetings with case managers, to regular attendance at a day program. Greater numbers of received services and fewer unmet service needs were associated with a higher likelihood of engaging in any daytime activities. This highlights the significance of both formal and informal support systems in shaping the lives of individuals with disabilities (Taylor & Hodapp, 2012).

Social Supports

A survey study involving 126 adults with autism found that 49% of less cognitively able adults had any social contacts outside of the family, while 53% of those who were more cognitively able had one or more friends (McCauley et al., 2020). This lack of social support among people with ASD may negatively impact their self-determination. Social interactions, mutual agreements, and respectful support were identified as crucial elements in enhancing self-determination for individuals with IDD (Wehmeyer & Bolding, 2001).

Mindfulness

Mindfulness training for caregivers of individuals with profound multiple intellectual disabilities demonstrated a positive impact on the happiness of individuals with profound multiple intellectual disabilities during leisure activities. This suggests that mindfulness practices among caregivers can enhance the social and emotional support provided to individuals with IDD (Singh et al., 2004). Examples of mindfulness practices are meditation, journaling, and grounding exercises. Moreover, caregivers who have undergone mindfulness practices may exhibit characteristics such as responsiveness, non-judgmental attitudes, and adaptability, thereby serving as natural supports for individuals with IDD (Singh et al., 2004).

Religion/Spirituality

Religiosity and spirituality can be major factors in the well-being of an individual with IDD, along with their entire family or caregiving dynamic (Boehm & Carter, 2019). This could be due to the feelings of safety, “peace of mind” and hope that come from increased religiosity/spirituality (Boehm & Carter, 2019). However, local religious congregations can be inaccessible, or lacking in social supports for families that have members with disabilities. This could be circumvented through a targeted intervention or education with churches about the benefits of disability inclusion and representation.

Organizational Supports

Another study examined data from 800 older individuals (55 years and older) with severe disabilities using the Personal Outcome Measures® data (Friedman, 2019). In looking at quality-of-life outcomes, older adults with severe disability had less than half of the 21 quality-of-life outcomes measured. For example, the majority lacked community integration, relationships, choices, and opportunities in their lives. These lack of quality-of-life outcomes could be related to lack of support to achieve these outcomes. There is a great need for these individuals to receive organizational support that is individualized to their needs so they can enhance their quality of life outcomes (Friedman, 2019).

Health & Psychosocial Health Supports for People With IDD

As discussed in the previous section, individuals with IDD benefit significantly from being connected to natural support networks. Besides the social and instrumental supports, having natural support networks also lead to positive health-related outcomes such as safety, freedom from abuse, and optimal health (Friedman, 2023). Despite these potential benefits, adults with IDD face higher obesity rates across all age groups compared to the general population (Hsieh et al., 2014). While some factors associated with obesity are non-modifiable, such as gender and having Down syndrome, targeted interventions can address modifiable factors such as medications, physical activity, TV-watching, and soda consumption (Hsieh et al., 2014).

Childhood adversity, including experiences like living in foster/group homes, parental divorce or separation, and bullying, is linked to a higher prevalence of medical illness and poorer quality of life in adults with IDD (Santoro et al., 2018). Tailored health support interventions should consider these unique health profiles influenced by childhood adversity, including high rates of allergies, urinary/kidney trouble, thyroid issues, and a history of depression (Santoro et al., 2018).

In focus groups involving people with IDD and their family members, concerns about health diverged. Individuals with IDD expressed worries about diet, exercise, and weight management, while family members focused more on risk management and self-advocacy for their loved ones with IDD (Krahn et al., 2023). The psychosocial impact of accessibility issues, dependence on others, and social isolation on personal dignity is a significant challenge faced by people with IDD (Fresher-Samways et al., 2003). As adults with IDD enter later-life phases, addressing their evolving psychosocial and mental well-being becomes crucial (Sullivan et al., 2019). Family members provide important advocacy to ensure their family member with IDD gets the best care from health professionals (Krahn et al., 2023).

The ability of individuals with IDD to choose their own support services correlates with positive psychosocial outcomes, including safety, freedom from abuse, social integration, and community participation (Friedman & VanPuymbrouck, 2019). Employment emerged as a key factor in creating social connections, fostering a sense of belonging, and contributing to the social support system for individuals with IDD (Carter et al., 2023). Disparities based on race are evident, with Black Indigenous People of Color (BIPOC) facing ableism and racism in their communities, impacting their quality-of-life outcomes (Friedman & VanPuymbrouck, 2019).

Positive outcomes for adults with ASD are associated with higher verbal IQ, greater daily living skills, and increased happiness (McCauley et al., 2020). In comparing employment settings, competitive employment is linked to enhanced objective quality of life and material well-being, while work center employment (sometimes referred to as “sheltered workshops”) shows higher scores in social-related domains (Randall et al., 2023). The absence of activities, particularly vocational or educational, contributes to higher levels of behavioral, health, and functional problems in adults with IDD, highlighting the importance of intervention and support (Taylor & Hodapp, 2012).

Self-care is a vital factor in quality of life of individuals with intellectual and developmental disabilities (Hankle et al., 2022). Self-care comes in a variety of formats (e.g., technology, music, sports), but people with IDD, and people without disabilities, have similar wants and needs surrounding self-care (Hankle et al., 2022).

HealthMatters is a program developed at the University of Illinois Chicago that aims to improve the health of people with IDD. The program is an evidence-based 6-hour training that provides structured information on how to organize and start a tailored physical activity and health education program for people with IDD (Marks et al., 2010).

Self-Determination/Autonomy Supports for People With IDD

Participating in formal self-advocacy is a common source of pride for many individuals with IDD. Additionally, family empowerment has been shown to increase family resilience (Caldwell et al., 2018). However, a qualitative study conducted in 2003 revealed that while some adults with IDD expressed feelings of empowerment and self-advocacy in their lives, a significant portion faced frustrations and unwanted external input in decision-making (Fresher-Samways et al., 2003).

It is crucial for professionals working with individuals with IDD to provide opportunities for learning and practicing skills related to self-determination, including those with lower intellectual capacities (Wehmeyer & Palmer, 2003). A yoga intervention program designed for adults with IDD showcased how fostering autonomy, relatedness, and competence through yoga supported self-determination (Allison et al., 2021). The interactive nature of the sessions, allowing varied expressions and participant-initiated physical contact, contributed to empowering individuals with IDD.

Insights from focus groups involving various stakeholders, including people with IDD, family members, and professionals, underscored the importance of honoring the person with IDD's agency in healthcare decision-making (Krahn et al., 2023). One family member succinctly captured this sentiment by stating, "Dignity is really about informed choices and not assuming the person doesn't deserve to understand the information and their choices" (Krahn et al., 2023, p. 313). A study of 129 adults with DD found that when people are given environmental support and the time and space to practice doing tasks around the home (instead of having tasks done for them by family or support staff), they can do a lot more than they realize (Hutchings & Chaplin, 2017). Another study with adults with Down syndrome found that they were happier when they were given high expectations for independence (Thompson et al., 2020). Creating opportunities for autonomy in activity choice and creating opportunities for social interaction can result in increased happiness for individuals with disabilities (Darling & Circo, 2015; Davis et al., 2004).

When individuals with IDD are given the opportunity to choose their own services, there is a notable improvement in their overall quality of life (Friedman & VanPuymbrouck, 2019). Moreover, those who exhibit higher levels of self-determination are more likely to achieve financial independence, engaging in tasks such as maintaining a banking account, purchasing groceries, and accessing benefits (Wehmeyer & Palmer, 2003). Having a key to their own home and the ability to lock their own bedroom emerge as predictors of self-determination for people with IDD, as indicated by a study conducted by Jones and colleagues (2018). Conversely, the presence of a behavior plan was found to be negatively related to overall self-determination, self-regulation, and self-realization. To address this, practices that involve greater engagement of adults in developing their behavior plans may serve as a means of mitigating these negative effects (Jones et al., 2018). Natural support networks also play a pivotal role in the self-determination of individuals with IDD, influencing their ability to exercise rights, choose where to live and work, and decide on personal goals (Friedman, 2023). This positive impact on autonomy, self-determination, and person-centered practices underscores the importance of fostering such support networks.

Employment Supports for People With IDD

The employment landscape for individuals with IDD is multifaceted, encompassing not only economic considerations but also psychosocial well-being and community engagement. Understanding these nuances is essential for developing policies and interventions that foster meaningful and fulfilling employment experiences for this population.

Qualitative interviews conducted with adults with IDD shed light on the paramount importance of employment and economic security in their lives (Fresher-Samways et al., 2003). However, the findings from these interviews also pointed to prevalent challenges such as underemployment, a lack of advancement opportunities, and overall dissatisfaction with work situations. Steady employment positively influences the psychosocial health of individuals with IDD. Carter et al (2023) emphasize that having a job not only instills a sense of pride, self-confidence, and self-esteem but also contributes significantly to overall flourishing, happiness, and well-being (Carter et al., 2023).

A case study focusing on increasing self-determination for three workers with IDD, conducted by Reid (2001), highlighted the significance of adaptive devices. The study revealed that workers who were given the opportunity to use adaptive devices required less job coach support when utilizing adaptive devices, leading to decreased worker assistance percentages, and indicating a higher level of independence during work activities. Providing individuals with severe disabilities the opportunity to make choices about their work conditions is identified as a crucial aspect of self-determination, and the ability to control a major aspect of their work activities serves as a pathway to enhancing independence (Reid et al., 2001).

Another study focused on 126 adults with autism revealed a correlation between cognitive ability and employment. Those with higher cognitive abilities were found to be more likely to secure regular employment, with a notable 68% compared to 19% for those with lower cognitive abilities (McCauley et al., 2020). Furthermore, the type of employment has a significant impact on subjective Quality of Life (QoL) for individuals with IDD. Those engaged in competitive employment reported the highest QoL scores, followed by participants in work centers, with the unemployed ranking lowest in subjective QoL (Randall et al., 2023). Participants in sheltered workshops reported less community involvement, indicating a potential trade-off between the security of such environments and broader community engagement (Randall et al., 2023).

Tools and Instruments Identified

In the thriving research, a tool called the Comprehensive Inventory of Thriving (CIT) was developed by Su and colleagues (2014) that measures psychological well-being and predicts important health outcomes for individuals. The CIT includes 18 subscales and 54 items total covering a broad range of components related to psychological well-being. They also developed and validated a shorter version called the Brief Inventory of Thriving (BIT) which includes 10 total items and can be used as a screening tool of mental health and an indicator of psychological well-being (Su et al., 2014).

As part of the initial search methodology, the team marked any articles which appeared to use some sort of tool or instrument in their analysis. This resulted in 147 flagged articles. Researchers noted the title of each measurement instrument or scale used in these flagged articles. This resulted in 262 different instruments. Of these, 87 were removed from consideration based on exclusion criteria, leaving 175 instruments for review (see Table 3).

Table 3. Exclusion Criteria for Tools and Instruments

Reason for Exclusion	# of Articles
Not English Language	20
Clinical Diagnostic Tool	9
Doesn't Pertain to Main Concepts	7
Population Under 18	31
Duplicate	13
Other (e.g. tool was inaccessible)	7

The remaining 175 instruments included measurements for Mental Health (n=43), Quality of Life (n=30), Functioning (n=19), Family (n=18), Resilience (n=18), Self-Determination (n=11), Health (n=10), Health (n=10), Social Supports (n=9), and Other (n=17) (see Table 4).

Table 4. Type of Instrument

Type of Instrument (n=175)	
Mental Health	43
<ul style="list-style-type: none">• Other = 17• Depression = 9• Well-being = 6• Stress = 6• Anxiety = 2• Loneliness = 2• Mindfulness = 1	
Quality of Life	30
<ul style="list-style-type: none">• General Quality of Life = 26• Happiness = 4	
Functioning	19
<ul style="list-style-type: none">• Functional Support Needs = 14• Activities of Daily Living = 4• Behavior = 1	
Family	18
<ul style="list-style-type: none">• Other Family = 10• Impact/Burden = 4• Family Functioning = 4	
Resilience	18
<ul style="list-style-type: none">• General Resilience = 7• Coping = 8• Hope = 3	
Self-Determination	11
Health	10
Social Supports	9
Other	17

The research team will examine these tools further when developing the survey and focus group protocols. The research team will determine which questions or scales could be used or adapted for adults with IDD and their family caregivers.

Gaps in the Literature Identified

This environmental scan revealed several important gaps in the research and directions for future studies. We will take these gaps under advisement when designing the survey and focus group protocols for aging family caregivers and adults with IDD in Florida.

Inclusion of Multiple Family Perspectives

The family members of people with IDD and the person themselves tend to have lives which are deeply intertwined. This necessitates considering formal and informal supports for people with IDD together, as part of a package of “integrated supports” (Sanderson et al., 2019). Much of the literature within this environmental scan focused on one particular family member, often mothers of people with IDD (Heller et al., 2000; Kim et al., 2003; Parish et al., 2004; Pruchno, 2003; Pruchno & Meeks, 2004; Shivers et al., 2016) or typically developing siblings of people with IDD (Lee et al., 2019a, 2019b, 2020; Nuttall et al., 2018; Orsmond & Seltzer, 2009; Rossetti et al., 2020; Rossetti & Hall, 2015; Sanderson et al., 2019; Shivers, 2019; Taylor et al., 2008; Taylor & Hodapp, 2012; Tomeny et al., 2017; Wolfe et al., 2014). There was one article related to grandparents (Heller et al., 2000) and only a couple of articles that discussed fathers as part of parent research (Ha et al., 2008; Homan, Greenberg, & Mailick, 2020), though there were no articles specific to fathers. It is important to consider that “one family member cannot serve as a proxy for the perspective of an individual with IDD” (Burke et al., 2019, p. 39).

Conducting focus groups with various stakeholders, Krahn et al. (2023) discovered that when determining what health data is most important for adults with IDD, answers varied based on which group was being asked. Separate focus groups involved researchers/practitioners, persons with IDD, and family members, and all brought an important and unique perspective to the conversation. Including multiple family perspectives revealed the way each person’s contribution overlapped or diverged from others within the family unit.

Including the perspective of the persons with IDD themselves is particularly important and may require creative approaches to communicating if the participant is not verbal or has other communication challenges. Including the person with IDD within the research helps to determine how “the views and preferences of individuals with IDD converge or diverge from those of their family member” (Carter et al., 2023, p. 154). Consulting multiple informants from the family as part of standard research methodology “allow[s] for a more comprehensive view of the constructs of interest” (Tomeny et al., 2017, p. 112).

Research on families of people with IDD must move toward a more holistic approach, considering the perspectives of multiple members of the family group, including mothers, fathers, siblings, grandparents, the person with IDD and more. The intertwined and interdependent nature of families means that a distinction between interventions for the person with IDD vs. siblings vs. parent caregivers is more nebulous than it may appear. Research and interventions targeting whole families, including all members, can give a more complete picture of the evolving supports which help them thrive. More family-centered planning needs to be incorporated while designing and implementing supports and services that are tailored to the unique needs of family caregivers as well as their family members with IDD.

Longitudinal Methods

While the majority of studies included in this environmental scan used interview, focus group, or survey methodology, many researchers highlighted the advantages of using longitudinal methods for future research. The use of longitudinal methods would improve the ability to understand complex family dynamics throughout the life course. A longitudinal approach would be helpful for measuring health factors (Cha & Crosnoe, 2022), well-being (Mailick Seltzer et al., 2001), intergenerational ambivalence (Namkung et al., 2018, 2020), sibling relationships (Namkung et al., 2020; Orsmond & Seltzer, 2009; Rossetti et al., 2020; Tomeny et al., 2017), grandparent relationships (Heller et al., 2000), and parent-child relationships (Avieli et al., 2022; Greenberg et al., 2004; Mailick Seltzer et al., 2001; Marsack-Topolewski et al., 2023; Pruchno, 2003) over time as they shift and change. In all families, dynamics change over time, and this is especially true for families of people with IDD. While families grow, a sense of resilience and unity may develop as they learn to work together to provide support and create an inclusive environment. Longitudinal analyses of attitudes and supports needed by families could help reveal how patterns of need and service use change as families progress through the stages of aging and life transitions (Marsack-Topolewski et al., 2023).

The impact of various types of interventions for families of people with IDD would also provide a more robust understanding of their efficacy as well as their pertinence to families at different life stages. This could include the impact of mindfulness training (Bazzano et al., 2015; Singh et al., 2004), interventions focused on optimism for parent caregivers (Greenberg et al., 2004), the use of peer mentors for families navigating complex service systems (Marsack-Topolewski et al., 2023), and future planning such as The Future is Now (Arnold et al., 2022). In each of these cases, longitudinal follow-up would enable researchers to observe trends, patterns, and sustained effects of the intervention (Su et al., 2014).

Measuring Complex Concepts

Measuring complex and theoretical concepts such as coping (Kim et al., 2003; Piazza et al., 2014), stress (Bazzano et al., 2015; Pruchno & Meeks, 2004; Wong & Shobo, 2017), guilt (Shivers, 2019), self-determination (Allison et al., 2021; Jones et al., 2018; Reid et al., 2001; Wehmeyer & Bolding, 2001; Wehmeyer & Palmer, 2003), or well-being (Esbensen et al., 2013; Greenberg et al., 2004; Ha et al., 2008; Kim et al., 2003) pose a considerable challenge to researchers due to their inherently subjective and multifaceted nature. These abstract ideas often lack universally agreed-upon definitions, making it difficult to design standardized measurement tools.

Limitations of the Scan

There are a few limitations of this environmental scan. First, the environmental scan in its nature is limited in the amount of literature (and instruments/scales) that can be reviewed and utilized within this scan. By definition, an environmental scan is meant to capture an overview of the literature instead of a comprehensive and in-depth review. Because of this, results may not be as exhaustive as similar analytic methods such as a scoping or systematic review. Second, the scan was limited in the amount of “grey literature” (i.e., non-peer-reviewed literature such as policy briefs, news articles, or other non-academic literature). Third, the number of articles and grey literature that were able to be reviewed was limited due to time constraints of the scan. The scan was completed in less than 7 months to begin the next phase of the project. As a result, the scan may not have captured all the literature on the relevant topics and may be missing some aspects of the noted topics. While these limitations should be taken into consideration when reviewing this report, the report also serves as a solid foundation of information for the next steps of the project.

Implications

Thriving as a Framework for Future Research Practice and Policy Development

This project takes an innovative approach by using the lens of thriving to explore the experiences of people with IDD and their aging families. The research questions for this project ask the following:

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

To understand what thriving looks like for people with IDD and their aging families, we need to measure thriving. We are using the definition of thriving from Su and colleagues that states: “Thriving is the state of positive functioning at its fullest range—mentally, physically, and socially” (Su et al., 2014).

The Comprehensive Inventory of Thriving has the following components to measure:

1. Relationships support looks at community, trust, respect, loneliness, and belonging;
2. Engagement;
3. Mastery of skills looks at learning, accomplishment, self-efficacy, and self-worth;
4. Autonomy looks at control or lack of control;
5. Meaning looks at meaning and purpose;
6. Optimism; and
7. Subjective well-being looks at life satisfaction, positive feelings, and negative feelings.

Using this tool and the relevant instruments or scales within the instruments derived from the literature search, we will be able to capture ways aging families of people with IDD are thriving.

Include Multiple Family Perspectives in Research

There is a need to include multiple family perspectives in research on adults with IDD and their aging families. In particular, importance needs to be given to include the perspectives of multiple members of the family. Though there is a need to highlight the problems of only targeting resources/support for families or people with IDD separately, there is also a crucial need for integration of supports and services because of overlap and interdependence.

Recognize Resource and Support Barriers

Less than 15% of people with IDD receive formal out-of-home Long-Term Services and Supports (Braddock et al., 2015). Instead, 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 loved ones with disabilities” (Friedman, 2023, n.p). Lee et al. (2019) found that limited quality programs for adults with IDD, financial costs, and system navigation were all significant barriers to families receiving adequate support. While studying a range of issues important to families of people with IDD, it is important to consider the nearly ubiquitous experience of facing systemic barriers to accessing supports and services, with these systems consistently failing to meet families’ needs.

Build on Previous Work That Bridges Aging and Disability

There is much that can be learned by bridging aging and disability networks. This project builds on the previous work, including Florida’s AGEDD project, the Project of National Significance on Bridging Aging and Disability Networks, and work related to the RAISE Act.

Florida’s AGEDD project, led by Margaret Lynn Duggar and Associates, Inc., conducted a study to capture the state of the state on both aging and DD in Florida. They identified key issues facing aging families of individuals with IDD. A roadmap was developed for systems change efforts between the aging and DD networks in Florida. As recommendations from their 2021 report have been implemented, they shifted gears to have community partnership calls where a contact from the aging service system connects with a contact from the DD service system. Through these calls, they have seen relationships develop across the two systems and ideas have naturally emerged for ways they can work together.

The Project of National Significance on Bridging Aging and Disability Networks is funded by the Administration on Community Living and led by the National Association of Councils on Developmental Disabilities. The 5-year grant (10/1/21-9/30/26) is building 15 State Alliance Teams (SAT) and a national Community of Practice (CoP) that includes members from the aging and disability network systems to learn from each other. Each state develops a workplan that guides change within their state. The goal is to strengthen the collaboration between aging and disability networks to better support individuals with IDD and their families as they plan for their future across the lifespan. The Florida DD Council is the lead for the Florida Statewide Alliance Team and part of the national Community of Practice.

The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren focuses on ways to support aging family caregivers. In taking a multipronged approach to improve the lives of family caregivers, they produced the 2022 National Strategy to Support Family Caregivers: Federal Actions, which include over 300 actions that 15 federal agencies plan to focus on. Additionally, there is a companion document on Actions for States, Communities, and Others, which conveys more than 150 actions other entities can take. Additionally, they created a document with principles on Cross-Cutting Considerations for Family Caregiver Support, which highlights workforce considerations including person- and family-centered approaches. These strategies will evolve based on public feedback and be responsive to the caregiving environment.

For this project, we will use the previous and extensive work completed to build upon the foundation. We hope to learn new information using the innovative approach brought by the lens of thriving so that recommendations can be made which could lead to actions that improve the lives of adults with IDD and their aging family caregivers.

Next Steps

Moving forward, we will be creating the assessment tools for the current study, including a survey and focus group protocols. We will work with Florida's Statewide Alliance Team (SAT), which is called the Aging Caregiver Task Force, comprised of key experts from across the state including family members and people with IDD to develop the survey and the focus group protocols. The survey will be administered to the aging family caregivers. The focus groups will be conducted with both adults with IDD and family caregivers separately.

We will also pilot test the focus group protocols with people with IDD and families. Findings from the pilot tests will be used to refine and finalize the data collection instruments. The survey will be conducted with families of adults (Ages 21 years and older) with IDD throughout Florida. The focus groups will include families of adults (Ages 21 years and older) with IDD, along with individuals with IDD, throughout Florida as two separate and simultaneously occurring focus groups. There will be four focus group sessions, with two separate groups occurring at each session. Each focus group will include at least 10 participants. Our goal is to reach at least 300 participants across the state.

Recruitment will be done in partnership with the Florida DD Council and their partners to ensure the survey and focus groups reach families across the state. A recruitment plan will be developed by FDDC with input from the Statewide Alliance Team. This will include partner organizations throughout the state who will serve as bridge builder

organizations to help with recruitment. This could include provider and advocacy organizations, faith-based organizations, the University Centers for Excellence in Developmental Disabilities, and more. We will work with the FDDC to create recruitment materials that are clear and accessible. We will make sure to specify the definition of IDD used in Florida and include screening questions to ensure we are capturing information from the people we are intending to learn from. All participants will be 21 years and older.

Efforts will be made to gather information from hard-to-reach and underserved groups, including people in rural locations across the state. This will include translating and culturally adapting the data collection instruments for Spanish speaking families and holding at least one focus group in Spanish. We will work with the FDDC to identify cultural brokers to help with recruitment of Spanish speaking participants. Additionally, we will work with FDDC to identify if other languages and cultural adaptations should be made to the data collection instruments and if additional cultural groups should be focused on.

For the families that complete the survey, we will include a survey question asking if they would also like to participate in a focus group on this topic. We will use these responses as a starting point to recruit for the focus groups. We will work with FDDC to identify which parts of the state to focus on for recruitment of the focus groups for both families and adults with IDD. Once the data is collected, we will analyze it to identify the ways that families of people with IDD thrive in Florida. The findings will be shared with FDDC and the Statewide Alliance Team to help inform resources to support aging families of people with IDD as they strive to thrive. The Statewide Alliance Team will be engaged in each step of the process to provide their guidance and expertise.

There will be six main outcomes from this project. First, a comprehensive survey tool will be developed to administer to families of people with IDD to capture what helps them thrive. Second, focus group protocols will be developed to conduct focus groups with adults with IDD and their family caregivers to understand what helps them thrive. Third, a translated and culturally adapted version of the data collection instruments for Spanish speaking families will be developed. Fourth, data will be collected from over 300 participants, including aging family caregivers and adults with IDD on what helps them thrive. Fifth, recommendations for future initiatives to support families of people with IDD to thrive will be provided. Sixth, results that will help inform the development of resources to support aging families of people with IDD as they strive to thrive will be shared.

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Appendices

Appendix A. Input from Stakeholders

Date of Aging Task Force Meeting	Notes and Other Input from Meeting
July 20, 2023	<ul style="list-style-type: none"> • Future planning should be specified. Many families don't realize it's a need. Mental health & wellbeing are also tied to future planning. It's an unmet need in the literature, but it might not be deemed that by families. • Geography/topography is something to consider. Thriving in a liberal community like Miami is very different from a suburban community like Tallahassee. • Maybe we can examine this further- what are certain areas learning from others. • Resources vary greatly by area too. Rural are probably dependent on churches and neighbors. • There are no guarantees how long we'll be here. Future planning is important. • Is financial planning included in future planning? Other specific aspects like long-term care. Access to Medicaid is something to consider. • There is a knowledge gap on the aging side about DD services, and vice versa. An "intentional statement" about this lack of a bridge should be included in the environmental scan. • Lack of education surrounding Medicaid vs. Medicare and how the services differ. • Caregivers are not always family members. Family members are not always the caregivers for specific services. • Difficulties in access are a big hurdle. • Lots of time is spent gathering data, but there is a worry about how this data will be disseminated and used or applied. • A research paper that just gets filed is not the goal, we have a commitment to systems change.
October 19, 2023	<ul style="list-style-type: none"> • Culture could play a role in thriving, or even in definitions of thriving. • Aiming to include dads in the focus group discussion, as moms are usually the focus in this area of research.

- Considering Miami as a location makes sense as it has unique cultural dynamics and a huge immigrant population which can impact access to resources.
- Tampa is also a good area to consider.
- It will be interesting to see what people do or consider “thriving” via unpaid resources/tools.
- What we find in Tallahassee will be different from Miami and Orlando
- Having separate but simultaneous focus groups is a great idea, and we will have to consider how we can reconcile differing opinions.
- This focus group format can also crosswalk between families in the write-up, to see if there are any contrasting opinions or differing needs.
- People who are not getting services/are on waitlists will hopefully be represented in the focus groups.
- Only 6% of the Florida population is served by the IDD agency (Either on the waiting lists or directly getting services). There are many folks who are not involved with the formal networks.
- It will be interesting to see the survey options (Online, a call-in option, paper, etc.). The decision should be made based on what previous research has utilized to make it easy and convenient.
- Language barriers will be a large challenge. There is a lack of communication from service providers in languages other than English.
- The survey should ask if families are actively on any waiting lists or if they are actively receiving any services.
- Service organizations like the Rotary Club, Kiwanis, Shriners, and other organizations should be utilized for recruitment.

Appendix B. Search Terms

Concept	Synonymous Search Terms
Aging	Aging, Geriatric* (Geriatric, Geriatrics, etc.), Elder* (Elder, Elderly, etc.), Old* (Old, Older, etc.)
Intellectual & Developmental Disability	Disab* (Disabling, Disability, etc.), Intellectual Disab* (Disabilities, Disabled, etc.), Developmental Disab* (Disabilities, Disabled, etc.)
Families	Famil* (Family, Families, etc.), Parent* (Parents, Parenting, etc.), Child* (Child, Children, etc.), Sib* (Sibling, Siblings, etc.), Grandparent* (Grandparent, Grandparenting, etc.)
Thriving	Thriv* (Thrive, Thriving, etc.), Resilience, Quality of Life, Well-Being, Flourish, Self-Actualization, Self-Determination, Happiness

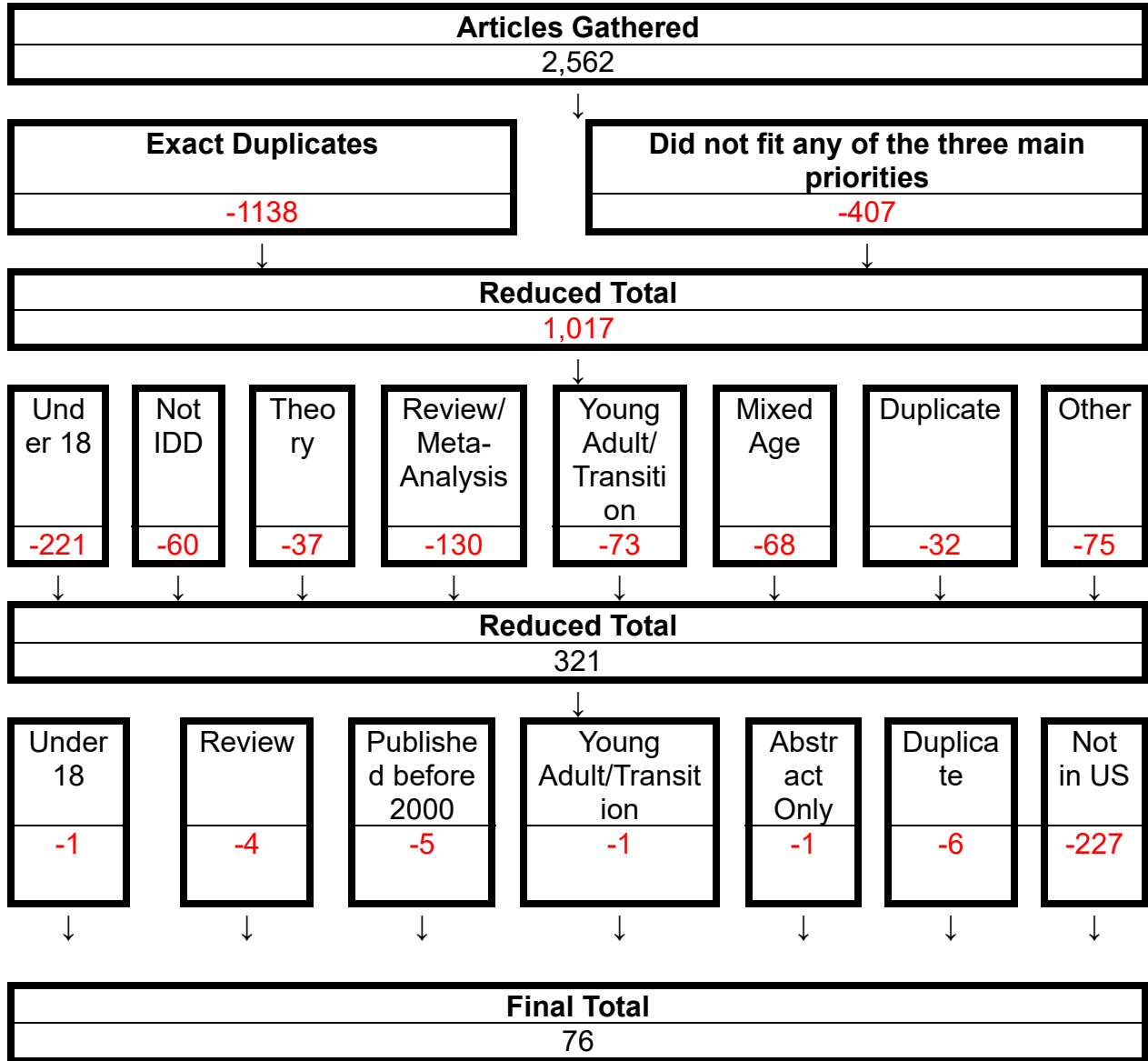
This yielded a total of 329 unique combinations of search terms.

Appendix C. List of Web Sites Reviewed

Name and Hyperlink of Website or Database
<ul style="list-style-type: none">• <u>PubMed</u>• <u>APA PsycINFO</u>• <u>Google Scholar</u>• <u>Scopus</u>• <u>UIC Library Home Page</u>

Appendix D. Data Abstraction Protocol

Table 5. Article Reduction



Appendix E. Peer-Reviewed Articles Included in Final Review

	Title	Citation
1	Juggling between caregiving and self-actualization: Older parents' lifelong experience of caring for an adult child with developmental disabilities	Avieli, H., Band-Winterstein, T., & Zamir, A. (2022). Juggling between caregiving and self-actualization: Older parents' lifelong experience of caring for an adult child with developmental disabilities. <i>PLoS One</i> , 17(11), e0276779. https://doi.org/10.1371/journal.pone.0276779
2	Transition to retirement: The lived experiences of adults with intellectual disabilities	Anderson, L. L., Hall, S., Kramme, J. E. D., & Stancliffe, R. (2023). Transition to retirement: The lived experiences of adults with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities: JARID</i> , 36(3), 547–557. https://doi.org/10.1111/jar.13078
3	Types of Family Caregiving and Daily Experiences in Midlife and Late Adulthood: The Moderating Influences of Marital Status and Age	Wong, J. D., & Shobo, Y. (2017). Types of family caregiving and daily experiences in midlife and late adulthood: The moderating influences of marital status and age. <i>Research on Aging</i> , 39(6), 719–740. https://doi.org/10.1177/0164027516681050
4	The Relationship of Person-Environment Fit to Perceptions of Autonomy, Competency and Satisfaction Among Older Adults with Developmental Disabilities: Relationship of Person-Environment Fit to Perceptions	Hutchings, B. L., & Chaplin, E. (2017). The Relationship of Person-Environment Fit to Perceptions of Autonomy, Competency and Satisfaction Among Older Adults with Developmental Disabilities. <i>Journal of Policy and Practice in Intellectual Disabilities</i> , 14(3), 214-223. https://doi.org/10.1111/jppi.12175
5	Exploring the nature and correlates of caregiving among parents of adults with intellectual and developmental disabilities	Burke, M. M., Rios, K., Aleman-Tovar, J., Lee, C. E., Arnold, C. K., & Owen, A. (2020). Exploring the nature and correlates of caregiving among parents of adults with intellectual and developmental disabilities. <i>Journal of applied research in intellectual disabilities: JARID</i> , 33(6), 1259–1267. https://doi.org/10.1111/jar.12745
6	Effects of parenting adults with disabilities on later-life health: The role of intergenerational ambivalence.	Namkung, E. H., Greenberg, J. S., Mailick, M. R., & Floyd, F. J. (2020). Effects of parenting adults with disabilities on later-life health: The role of intergenerational ambivalence. <i>Psychology and aging</i> , 35(2), 177–189. https://doi.org/10.1037/pag0000413
7	Lifelong Parenting of Adults With Developmental Disabilities: Growth Trends Over 20 Years in Midlife and Later Life	Namkung, E. H., Greenberg, J. S., Mailick, M. R., & Floyd, F. J. (2018). Lifelong Parenting of Adults With Developmental Disabilities: Growth Trends Over 20 Years in Midlife and Later Life. <i>American journal on intellectual and developmental</i>

		<i>disabilities</i> , 123(3), 228–240. https://doi.org/10.1352/1944-7558-123.3.228
8	Enmeshed Lives: Adult Children With Developmental Disabilities and Their Aging Mothers.	Pruchno R. A. (2003). Enmeshed lives: adult children with developmental disabilities and their aging mothers. <i>Psychology and aging</i> , 18(4), 851–857. https://doi.org/10.1037/0882-7974.18.4.851
9	Age and Gender Differences in the Well-Being of Midlife and Aging Parents with Children with Mental Health or Developmental Problems: Report of a National Study	Ha, J. H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: report of a national study. <i>Journal of health and social behavior</i> , 49(3), 301–316. https://doi.org/10.1177/002214650804900305
10	Long-term Impact of Parental Well-Being on Adult Outcomes and Dementia Status in Individuals With Down Syndrome	Esbensen, A. J., Mailick, M. R., & Silverman, W. (2013). Long-term impact of parental well-being on adult outcomes and dementia status in individuals with Down syndrome. <i>American journal on intellectual and developmental disabilities</i> , 118(4), 294–309. https://doi.org/10.1352/1944-7558-118.4.294
11	Generativity and Well-Being of Midlife and Aging Parents With Children With Developmental or Mental Health Problems	Homan, K. J., Greenberg, J. S., & Mailick, M. R. (2020). Generativity and Well-Being of Midlife and Aging Parents With Children With Developmental or Mental Health Problems. <i>Research on aging</i> , 42(3-4), 95–104. https://doi.org/10.1177/0164027519884759
12	Compound sibling caregivers of individuals with intellectual and developmental disabilities	Lee, C. E., Burke, M. M., Arnold, C. K., & Owen, A. (2020). Compound sibling caregivers of individuals with intellectual and developmental disabilities. <i>Journal of applied research in intellectual disabilities: JARID</i> , 33(5), 1069–1079. https://doi.org/10.1111/jar.12729
13	Caregiver resource utilization: Intellectual and development disability and dementia	Fleming, V., & Litzelman, K. (2021). Caregiver resource utilization: Intellectual and development disability and dementia. <i>Journal of applied research in intellectual disabilities: JARID</i> , 34(6), 1468–1476. https://doi.org/10.1111/jar.12889
14	The Effect of Quality of the Relationship Between Mothers and Adult Children With Schizophrenia, Autism, or Down Syndrome on Maternal Well-Being: The Mediating Role of Optimism.	Greenberg, J. S., Seltzer, M. M., Krauss, M. W., Chou, R. J., & Hong, J. (2004). The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or down syndrome on maternal well-being: the mediating role of optimism. <i>The American journal of orthopsychiatry</i> , 74(1), 14–25. https://doi.org/10.1037/0002-9432.74.1.14

15	Ripple effects of developmental disabilities and mental illness on nondisabled adult siblings	Wolfe, B., Song, J., Greenberg, J. S., & Mailick, M. R. (2014). Ripple effects of developmental disabilities and mental illness on nondisabled adult siblings. <i>Social science & medicine</i> (1982), 108, 1–9. https://doi.org/10.1016/j.socscimed.2014.01.021
16	Childhood Caregiving Roles, Perceptions of Benefits, and Future Caregiving Intentions Among Typically Developing Adult Siblings of Individuals with Autism Spectrum Disorder	Nuttall, A. K., Coberly, B., & Diesel, S. J. (2018). Childhood Caregiving Roles, Perceptions of Benefits, and Future Caregiving Intentions Among Typically Developing Adult Siblings of Individuals with Autism Spectrum Disorder. <i>Journal of autism and developmental disorders</i> , 48(4), 1199–1209. https://doi.org/10.1007/s10803-018-3464-6
17	Health Profile of Aging Family Caregivers Supporting Adults With Intellectual and Developmental Disabilities at Home	Yamaki, K., Hsieh, K., & Heller, T. (2009). Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. <i>Intellectual and developmental disabilities</i> , 47(6), 425–435. https://doi.org/10.1352/1934-9556-47.6.425
18	Quality-of-Life Outcomes of Older Adults with Severe Disabilities	Friedman, C. (2019). Quality-of-Life outcomes of older adults with severe disabilities. <i>Research and Practice for Persons with Severe Disabilities</i> , 44(4), 237-250. https://doi-org.proxy.cc.uic.edu/10.1177/1540796919879227
19	Evaluation of peer-mediated systems navigation for ageing families of individuals with developmental disabilities	Marsack-Topolewski, C., Milberger, S., Janks, E., Anderson, N., Bray, M., & Samuel, P. S. (2023). Evaluation of peer-mediated systems navigation for ageing families of individuals with developmental disabilities. <i>Journal of intellectual disability research: JIDR</i> , 67(5), 462–474. https://doi.org/10.1111/jir.13024
20	Supporting Aging Caregivers and Adults With Developmental Disabilities in Future Planning	Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. <i>Mental retardation</i> , 44(3), 189–202. https://doi.org/10.1352/0047-6765(2006)44[189:SACAAW]2.0.CO;2
21	Thriving with Down syndrome: A qualitative multiple case study.	Thompson, T., Talapatra, D., Hazel, C. E., Coleman, J., & Cutforth, N. (2020). Thriving with Down syndrome: A qualitative multiple case study. <i>Journal of applied research in intellectual disabilities: JARID</i> , 33(6), 1390–1404. https://doi.org/10.1111/jar.12767
22	Increasing the happiness of individuals with profound multiple disabilities: replication and extension	Davis, P. K., Young, A., Cherry, H., Dahman, D., & Rehfeldt, R. A. (2004). Increasing the happiness of individuals with profound multiple disabilities: replication and extension. <i>Journal of applied</i>

		<i>behavior analysis</i> , 37(4), 531–534. https://doi.org/10.1901/jaba.2004.37-531
23	Measuring happiness in individuals with profound multiple disabilities	Darling, J. A., & Circo, D. K. (2015). Measuring happiness in individuals with profound multiple disabilities. <i>Research in developmental disabilities</i> , 47, 117–125. https://doi.org/10.1016/j.ridd.2015.09.005
24	Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability	Gilbert, A., Lankshear, G. & Petersen, A. (2007). Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability. <i>International Journal of Social Welfare</i> , 17(1), 54-64. https://doi.org/10.1111/j.1468-2397.2007.00485.x
25	Coping and Psychological Health of Aging Parents of Adult Children With Developmental Disabilities	Piazza, V. E., Floyd, F. J., Mailick, M. R., & Greenberg, J. S. (2014). Coping and psychological health of aging parents of adult children with developmental disabilities. <i>American journal on intellectual and developmental disabilities</i> , 119(2), 186–198. https://doi.org/10.1352/1944-7558-119.2.186
26	Examining Predictors of Self-Determination in Adults with Intellectual and Developmental Disabilities	Jones, J. L., Shogren, K. A., Grandfield, E. M., Vierling, K. L., Gallus, K. L., & Shaw, L. A. (2018). Examining Predictors of Self-Determination in Adults with Intellectual and Developmental Disabilities. <i>Journal of Developmental and Physical Disabilities</i> , 30(5), 601–614. https://doi.org/10.1007/s10882-018-9607-z
27	Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments	Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. <i>Journal of intellectual disability research: JIDR</i> , 45(Pt 5), 371–383. https://doi.org/10.1046/j.1365-2788.2001.00342.x
28	Later Life Impacts of Social Participation on Parents of Adult Offspring With and Without Intellectual and Developmental Disabilities	Olsen D. L. (2018). Later Life Impacts of Social Participation on Parents of Adult Offspring With and Without Intellectual and Developmental Disabilities. <i>American journal on intellectual and developmental disabilities</i> , 123(1), 50–60. https://doi.org/10.1352/1944-7558-123.1.50
29	Doing Nothing: Adults With Disabilities With No Daily Activities and Their Siblings	Taylor, J. L., & Hodapp, R. M. (2012). Doing nothing: adults with disabilities with no daily activities and their siblings. <i>American journal on intellectual and developmental disabilities</i> , 117(1), 67–79. https://doi.org/10.1352/1944-7558-117.1.67

30	The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness	Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. <i>Journal of intellectual disability research: JIDR</i> , 47(Pt 4-5), 313–327. https://doi.org/10.1046/j.1365-2788.2003.00493.x
31	Obesity and associated factors in adults with intellectual disability: Obesity and ID	Hsieh, K., Rimmer, J. H., & Heller, T. (2014). Obesity and associated factors in adults with intellectual disability. <i>Journal of intellectual disability research: JIDR</i> , 58(9), 851–863. https://doi.org/10.1111/jir.12100
32	Ableism, racism, and the quality of life of Black, Indigenous, people of colour with intellectual and developmental disabilities	Friedman C. (2023). Ableism, racism, and the quality of life of Black, Indigenous, people of colour with intellectual and developmental disabilities. <i>Journal of applied research in intellectual disabilities: JARID</i> , 36(3), 604–614. https://doi.org/10.1111/jar.13084
33	Childhood adversity, health and quality of life in adults with intellectual and developmental disabilities: Adversity, health, & QOL in adults with I/DD	Santoro, A. F., Shear, S. M., & Haber, A. (2018). Childhood adversity, health and quality of life in adults with intellectual and developmental disabilities. <i>Journal of intellectual disability research: JIDR</i> , 62(10), 854–863. https://doi.org/10.1111/jir.12540
34	Association between employment status and quality of life for individuals with intellectual or developmental disability	Randall, K. N., Bernard, G., & Durah, L. (2023). Association between employment status and quality of life for individuals with intellectual or developmental disability. <i>Journal of applied research in intellectual disabilities: JARID</i> , 36(2), 270–280. https://doi.org/10.1111/jar.13053
35	Empowerment and Resilience in Families of Adults With Intellectual and Developmental Disabilities	Caldwell, J. A., Jones, J. L., Gallus, K. L., & Henry, C. S. (2018). Empowerment and Resilience in Families of Adults With Intellectual and Developmental Disabilities. <i>Intellectual and developmental disabilities</i> , 56(5), 374–388. https://doi.org/10.1352/1934-9556-56.5.374
36	Life Course Impacts of Parenting a Child With a Disability	Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. <i>American journal of mental retardation: AJMR</i> , 106(3), 265–286. <a href="https://doi.org/10.1352/0895-8017(2001)106<0265:LCIOPA>2.0.CO;2">https://doi.org/10.1352/0895-8017(2001)106<0265:LCIOPA>2.0.CO;2
37	Emotional and Tangible Reciprocity in Middle- and Older-Aged Carers of Adults With Intellectual Disabilities: Emotional and Tangible Reciprocity	Perkins, E. A., & Haley, W. E. (2013). Emotional and Tangible Reciprocity in Middle and Older-Aged Carers of Adults With Intellectual Disabilities. <i>Journal of Policy and Practice in Intellectual Disabilities</i> , 10(4), 334–344.

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