Evaluating the Benefits of a Family Support Program on the Health and Well-Being of Aging Family Caregivers of Adults with Intellectual and Developmental Disabilities

Article *in* Journal of Gerontological Social Work · August 2022

DOI: 10.1080/01634372.2022.2110347

Christina Marsack-Topolewski
Eastern Michigan University
65 PUBLICATIONS **394** CITATIONS

Elizabeth Janks
Wayne State University
5 PUBLICATIONS **3** CITATIONS

Nia Anderson
Wayne State University
1 PUBLICATION **2** CITATIONS

Michael Bray
Wayne State University
4 PUBLICATIONS **3** CITATIONS

Journal of Gerontological Social Work

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wger20

Evaluating the Benefits of a Family Support Program on the Health and Well-Being of Aging Family Caregivers of Adults with Intellectual and Developmental Disabilities

Sharon Milberger, Christina Marsack-Topolewski, Elizabeth Janks, Nia Anderson, Michael Bray & Preethy S. Samuel

To cite this article: Sharon Milberger, Christina Marsack-Topolewski, Elizabeth Janks, Nia Anderson, Michael Bray & Preethy S. Samuel (2022): Evaluating the Benefits of a Family Support Program on the Health and Well-Being of Aging Family Caregivers of Adults with Intellectual and Developmental Disabilities, Journal of Gerontological Social Work, DOI: 10.1080/01634372.2022.2110347

To link to this article: https://doi.org/10.1080/01634372.2022.2110347

JOURNAL OF GERONTOLOGICAL SOCIAL WORK
https://doi.org/10.1080/01634372.2022.2110347

Evaluating the Benefits of a Family Support Program on the Health and Well-Being of Aging Family Caregivers of Adults with Intellectual and Developmental Disabilities

Sharon Milberger[a], Christina Marsack-Topolewski[b], Elizabeth Janks[a], Nia Anderson[a], Michael Bray[a], and Preethy S. Samuel[a]

[a]Michigan Developmental Disabilities Institute & Department of Helath Care Sciences, Wayne State University, Detroit, Michigan, USA; [b]School of Social Work, Eastern Michigan University, Ypsilanti, Michigan, USA

ABSTRACT
Providing care to a family member with intellectual and developmental disabilities (I/DD) takes a toll on the health of the caregiver and the family, especially as they age. Research shows that peer mediated family support programs can improve caregiver health and well-being. To date, most family support programs have focused on family caregivers of children and youth with I/DD. The purpose of this study was to examine the benefits of participating in the Michigan Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN) family support program grounded in the Family Quality of Life (FQOL) framework. Specifically, we examined the effect of participation on health care utilization, caregiver well-being, and perceptions of global FQOL for older caregivers of adults with I/DD. Quantitative analysis of data gathered from 82 caregivers (age 50 and older) indicated that study participation was associated with increased use of Medicaid and improved caregiver well-being (reduced burden, stress, depression; increased health satisfaction and FQOL). Future research is needed to examine the long-term impact of the family support programs in improving the health and well-being of older caregivers of adults with I/DD.

ARTICLE HISTORY
Received 30 November 2021
Revised 2 August 2022
Accepted 2 August 2022

KEYWORDS
Aging; intellectual disabilities; peer mentoring; caregiving; health

In the United States, approximately 5.1 million children and 2.1 million adults are living with intellectual and developmental disabilities (I/DD; Tanis et al., 2021). The majority (72%) of individuals with I/DD reside with their family, with 24% of these individuals living with family caregivers aged 60 or older (Tanis et al., 2021). Similarly, in Michigan, 66% of the 225,925 adults with I/DD live with their families (Tanis et al., 2021). Family caregivers provide critical support to individuals with disabilities and chronic health conditions.

With a growing aging population, the number of older caregivers is rapidly expanding. Currently, more than half of family caregivers in the United States are older than 50, with nearly one in five above 65 years

CONTACT Preethy S. Samuel preethy@wayne.edu Wayne State University, 259 Mack Ave, Suite 2210, Detroit, MI 48201, USA

(American Associationof Retired Persons [AARP] & National Alliance for Caregiving, 2020). Research on family caregivers of individuals with I/DD indicates that they experience numerous adverse outcomes, including poorer health and quality of life (Javalkar et al., 2017; Whitley & Fuller-Thomson, 2018). Older caregivers often juggle their own aging-related needs, as well as navigate complex systems on behalf of their family members with I/DD (Marsack-Topolewski, 2020; Perkins, 2010). The competing demands of self-care and increased caregiving duties negatively affect older caregivers' health. Due to increasing life expectancy in the general population, aging caregivers are likely to continue in their roles for a longer time. The failure of older caregivers to plan for their future is concerning because sudden changes in the health capacity of the primary caregiver can put their adult child with I/DD at risk for losing their eligibility to benefits and supports. Some may even require placement in emergency residential facilities leading to a burden on the foster care system (Fifield, 2016).

Despite knowledge on challenges faced by families of adults with I/DD (Marsack-Topolewski, 2020), little is known about interventions in this population. Aging families face a variety of barriers when attempting to access services, such as lack of awareness of how to obtain from services, limited finances, and poor treatment by professionals (e.g., cultural insensitivity, use of professional jargon; Owen et al., 2021; Samuel et al., 2021). Many aging families do not use future planning services despite knowing that their children are likely to outlive them (Lee & Burke, 2020; Taylor et al., 2017). Emerging evidence suggests that peer support has the potential to empower aging caregivers of adults with I/DD by helping them to plan for the future. Peer-mediated support can provide aging families with skills and tools to improve individual and family health and well-being (Heller & Caldwell, 2006).

Conceptual framework

The family quality of life (FQOL) theoretical framework embodies a paradigm shift in disability service provision as it moves from fix to support, deficits to strengths, and individual to family as the focus of support (Samuel et al., 2012). Much of the focus of FQOL research to date has been among children with I/DD in several different countries, with a few exceptions that included aging families (Jokinen & Brown, 2005; Wang et al., 2022). The FQOL construct is defined as a "dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members [and] in which individual and family-level needs interact" (Zuna et al., 2009, p. 262). The FQOL approach emerged from several decades of QOL research focused on people with I/DD and therefore share similar measurement principles. The basic principles inherent to the FQOL framework are that FQOL is (Isaacs et al., 2007:

(1) Multidimensional and influenced by many factors.
(2) Comprised of similar dimensions for all individuals or groups, but that some aspects may hold more importance than others for some individuals or groups.
(3) Comprised of both subjective and objective elements.
(4) Best studied using qualitative and quantitative methodology.
(5) Studied for the specific purpose of understanding and improving the lives of individuals with disabilities and their families.

Health of the Family is a distinct domain of the international FQOL framework, along with the other eight domains: financial well-being; family relationships; support from others; support from disability services; influence of values; careers and preparing for careers; and leisure and community involvement (Isaacs et al., 2012). The domain of *health of the family* includes an evaluation of the dimensions of the opportunities, initiative, attainment, stability, and satisfaction with health of the family (Wang et al., 2022). Health care utilization of caregivers, which is the focus of the present study, is an objective indicator of these subjective dimensions of family health.

MI-OCEAN intervention

Given the underserved needs and lack of attention to aging family caregivers of adults with I/DD, a two-year grant from the Michigan Health Endowment Fund was used to implement the Michigan Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN) Family Support Project. The goal of the statewide project was to improve the health and well-being of older caregivers by developing and strengthening the healthcare workforce capacity and fostering system change through peer mentoring. MI-OCEAN program was an extension of a federally funded Project of National Significance that empowered low-income parents of color providing care for children with I/DD in southeast Michigan (Heller & Schindler, 2009). The MI-OCEAN program also was closely aligned with the Association for Children's Mental Health program to ensure that their Person Support Person (PSP) model was expanded to address adult and aging service systems in Michigan. The MI-OCEAN was based on the theoretical framework of FQOL to empower older family caregivers based on their strengths, challenges, and desires (Brown et al., 2006; Samuel et al., 2012).

The MI-OCEAN training curriculum for peer mentors known as family support navigators (FSNs) in this study was adapted from intervention manuals that were developed and refined progressively by key personnel and stakeholders involved in three family support projects (D*etroit 360 Family Support Project*: 2003–2010, *Easter Seals Family Support Project*: 2008–2009, *Michigan Family Support Initiative*: 2010–2012). Collectively, over 200 FSNs were trained to support families of young children with I/DD in Michigan. The modifications for the current project included adding information on aging related supports and services. The FSN training curriculum was grounded in the FQOL framework to support older caregivers in understanding key elements of service eligibility for brokering services and self-care as they transition through different life stages. The FSNs were trained on the elements of case coordination, record maintenance procedures, compliance requirements for state and local service programs, and the available funding mechanisms for family-centered service delivery of older families.

Past research indicates that peer mediated family support programs have the potential to improve the health and well-being of family caregivers (Berrick et al., 2011; Jamison et al., 2017; Joo et al., 2022). For example, Sung and Park (2012) report that connecting parents to the appropriate services reduced their stress and improved their FQOL. These programs work well when well-matched FSNs can use their personal and professional life experiences to build rapport and equip family members with tools to advocate for their adult children and themselves. To date, most family support programs have focused on caregivers of children and youth rather than caregivers of adults with I/DD (Cullen & Barlow, 2004; Rone-Adams et al., 2004; Zuurmond et al., 2019). Little is known in the context of older caregivers of adults with I/DD and hence the need for this study.

Study purpose

The purpose of this study was to examine the effects of participating in the MI-OCEAN family support program on health care utilization, caregiver well-being, and perceptions of global FQOL for older caregivers of adults with I/DD. The following research questions were addressed:

(1) To what extent did participation in MI-OCEAN change health utilization of older caregivers of adults with I/DD?
(2) To what extent did participation in MI-OCEAN change caregiver well-being and perceptions of global FQOL?

Methods

Study design and procedures

A one-group pretest-posttest design was used to determine the impact of the MI-OCEAN intervention on participants' health utilization, caregiver well-being and perceptions of global FQOL. The older caregivers completed a pretest that measured FQOL. Following the pretest, the FSNs worked with the caregivers as part of the intervention. At the completion of the intervention, the caregivers were posttested to determine changes that resulted from participation in the intervention. This approach measures the outcomes of interest before and after exposing a nonrandom group of participants to an intervention. Approval was obtained from Wayne State University's Institutional Review Board before conducting the study. Participants received $20 and $30 Visa gift cards upon completion of the baseline and final surveys, respectively.

Intervention

The MI-OCEAN program was offered to each participant by connecting them with a peer mentor, also known as a family support navigator (FSN) in this study. The FSNs were recruited through the Institute's website, social media, and caregivers who were already connected with ongoing training projects. Each FSN was at least 60 years of age with first-hand experience in advocating for and using family-centered disability services in Michigan on behalf of their adult family members with I/DD. The FSNs also understood the importance of cultural diversity in service provision of family centered services and were committed to completing the comprehensive two-day training program. To ensure geographical representativeness across the state, it was planned to recruit at least one FSN and 10 older caregivers from each of the 10 Prepaid Inpatient Health Plans (PIHPs) in Michigan. Because of turnover, four more navigators had to be hired. All FSNs completed a 2-day comprehensive training grounded in the FQOL framework. The Zoom platform was used to facilitate training because of their locations across the state. The training was intended to support FSN planning and included topics, such as service eligibility requirements, self-care, and transition planning across various life stages.

The target population for the MI-OCEAN project was family caregivers who were at least 60 years of age, providing support for at least one adult (22 years or older) with I/DD. Approval was obtained from the funding agency to lower the age of eligibility to 50 years for the caregiver and 18 years for the care recipient because of recruitment challenges, including the fact that several younger caregivers expressed the desire to participate in the study. After initial screening for eligibility and completing the intake process to determine the family's situation, level of need, and current access to services, participants were assigned to an FSN in their PIHP region by the Project Manager or research assistant who were both experienced at successfully matching navigators with families.

Each participant then received an e-mail with a link to complete the pretest survey that included an evaluation of FQOL. The project evaluator downloaded data from the Qualtrics site to conduct a preliminary analysis and develop an individualized FQOL report for each participant. The domain Health of the family was identified to be one of the top three domains of importance to their overall FQOL (*n* = 60, 74.1%) followed by family relationships (*n* = 45; 18.7), financial well-being (*n* = 38; 46.9%), and support form services (*n* = 32, 39.5%). The individualized report comprising graphs of the ratings of opportunity, initiative, attainment, stability, and satisfaction in each domain was returned to the project manager, who then in turn forwarded it to the FSNs. The project manager reviewed the report and then forwarded it to the FSNs. This evaluation process ensured the confidentiality of the caregiver's pretest responses on several indicators of caregiver health and well-being (e.g., stress, burden, depression), while providing essential information to guide the development of the

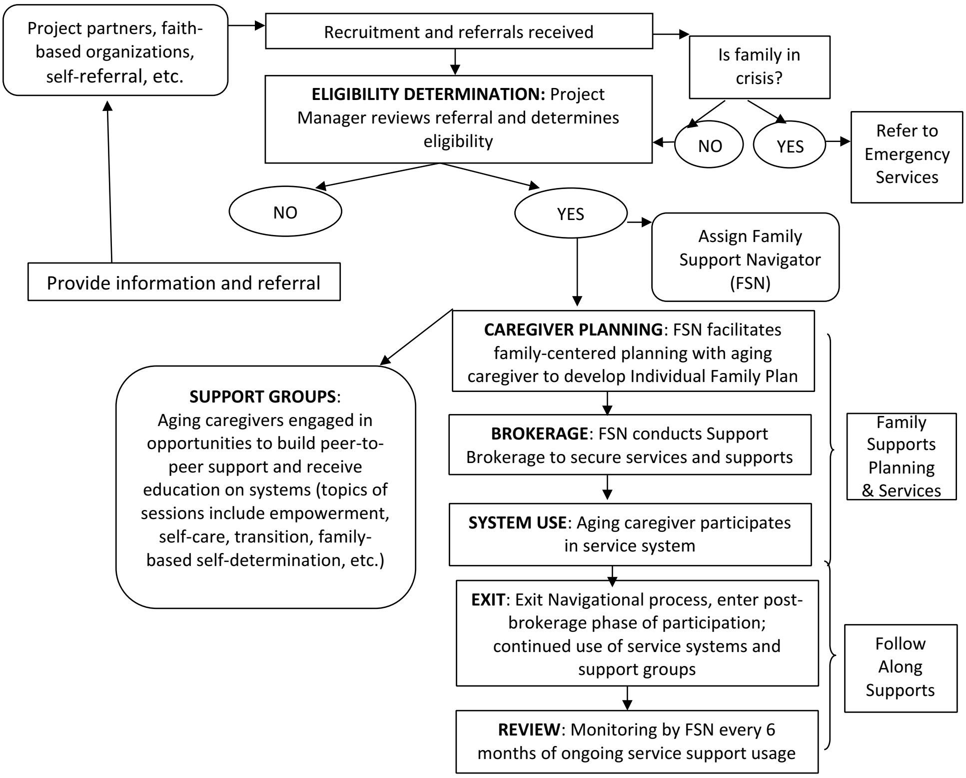

Figure 1. MI-OCEAN Procedural Model .

Individualized Action Plan (IAP). The FSN and caregiver jointly developed the IAP goals (1 long-term and 2 short term), as well as networking strategies to access diverse services and support for the family. As the length of intervention for each family to achieve the goals varied, their progress was evaluated every six months by the program manager (See Figure 1 for Procedural Model).

This program provided participants with a roadmap for navigating service systems to successfully achieve desired outcomes. The length of involvement in the intervention was unique to each family, depending on the time needed to attain the goals established with the FSNs. The program manager evaluated the progress of the participants in completing their goals every six months. The program manager convened 12 monthly FSN team meetings (2 in person, 10 virtual) to facilitate ongoing self-care, exchange system navigation experiences, and to provide information on topics of interest (e.g., evaluation, mindfulness). The topics of discussion included in each of the meetings are presented in Table 1. Each hour-long group session was facilitated by project staff and mixed social time with structured learning opportunities. Attendance varied from group to group, depending on the topic being presented. Typically, between 15–30 caregivers attended virtual meetings. Participants had opportunities to practice their new skills as they worked closely with their FSN to broker their individual service networks and support. Older caregivers learned how to contact resource personnel and use the correct language to access information. For example, asking for respite funding, instead of childcare. FSNs also modeled how to engage service providers, by roleplaying telephone calls with them, and then having the caregiver contact the agency, while the FSN observed the interaction. FSNs were paid for their efforts including mandatory training, navigation services, and monthly meetings.

Table 1. MI-Ocean FSN training curriculum.

Introduction	MI-OCEAN Project Summary: Project Goal and Objectives & Eligibility Requirements
Chapter 1	An Introduction to Peer Models of Practice: Building & Sustaining Successful Partnerships with Caregivers
Chapter 2	Resources for Caregivers
Chapter 3	Federal & State Resources for People with Developmental Disabilities
Chapter 4	Mindfulness Based Stress Reduction: Self Care and its Role in Quality of Life
Chapter 5	Multicultural Pluralism & Cultural Competency
Chapter 6	MI-OCEAN Family Quality of Life Assessment and Goal Setting for Caregivers
Chapter 7	Instructional Review Board, Confidentiality & Privacy
Chapter 8	Teaching Empowerment & Advocacy Skills to Caregivers
Chapter 9	Family Support & Family Centered Practices
Chapter 10	Developing the Individualized Action Plan
Chapter 11	Transition Planning and Fading
Chapter 12	Home Visiting, Safety and Confidentiality
Chapter 13	Grief & Loss

Participants

A family caregiver was defined as a parent, spouse, sibling, or other relative, excluding formal paid caregivers. Participants were recruited through the aging caregiving project e-mail listserv and the Michigan Developmental Disabilities Institute's Twitter and Facebook social media platforms. In addition, partnerships were established with the Michigan Department of Health and Human Services (MDHHS) Aging and Adult Services, the Michigan Autism Council, XXX Institute of Gerontology, The Arc Michigan, Autism Alliance of Michigan, Eastern Michigan University, and the Michigan Alliance for Families to access the statewide resources and networks for engagement of aging caregivers and families. Snowball sampling was used with participants asked to refer friends or others in their social networks with potential interest in participating.

Study recruitment occurred from May 2019 through December 2020. By March 2020, that marks the beginning of the pandemic related shut down of access to services for people with disabilities seeking routine health care services, only four of the 41 caregivers enrolled into the program had achieved their goals and exited the program. While the pandemic limited face-to-face meetings, recruitment and intervention continued via the phone, internet, and Zoom platforms. All home visits were canceled after the pandemic. Moving to an online format improved the FSNs' ability to meet caregivers and reduced geographic limitations. For example, FSNs with knowledge of statewide resources, were able to work with caregivers hundreds of miles away from their homes. However, this also meant that some caregivers were affected by limited access to the internet and computer or mobile phone.

One hundred participants submitted their pretest surveys online. Eighteen did not complete the post tests, with four dropping out of the study without implementing the IAP. The remaining 14 participants engaged with their FSNs and completed the study although they failed to complete the posttest surveys. No significant differences were found between demographic characteristics between the 82 caregivers who completed both pre- and posttests and the 18 caregivers who only completed pretests. The data analysis was based on 82 participants.

Instruments

A web-based survey was created using the Qualtrics Research Suite to gather information on the socio-demographic characteristics of the caregiver and the primary person with I/DD requiring support, the caregiving context, as well as their health and well-being. Gender, race, marital status, education, employment, caregiver relationship, living status, were categorical variables as described in Table 2. Annual family income and caregiving requirements in

Table 2. Family caregiver demographic characteristics (N = 82).

	N	%
Caregiver age (54–86 years)		
60 or below	18	22.0
61-65	20	24.4
66-70	25	30.5
71-75	12	14.6
76 and above	7	8.5
Gender (% Female)	69	84.1
Caregiver relationship		
Mother	61	74.4
Father	12	14.6
Sister	4	4.9
Other (nephew, aunt etc.)	5	6.1
Race* (*Participants could report multiple categories*)		
White	68	77.3
Black	8	9.1
Hispanic, Latino/Spanish	2	2.3
Asian American	5	5.7
American Indian/Alaskan native	1	1.1
Arab American	1	1.1
Other	2	2.3
Marital status		
Married or domestic partnership	61	74.4
Not married, divorced, widowed, separated	17	20.7
Single, never married	4	4.9
Educational level		
High school or below	12	14.6
Some college	11	13.4
Bachelor's/Associates degree	22	26.8
Graduate/Professional degree	37	45.1
Employment status		
Working full-time	19	23.2
Working part-time	9	11.0
Retired	30	36.6
Not working (e.g., homemaker, stay-at-home caregiver, disability)	22	26.8
Unemployed but looking for work	2	2.4
Family income		
Below $30,000	9	11.7
$30,000 to $59,999	18	23.4
$60,000–100,000	28	36.4
$Above 100,000	22	28.6
Missing	5	
Family size	*M*	*SD*
Total number of family members (1–10)	3.99	1.87
Family members needing care (1–5)	1.72	0.97
Living arrangements (% co-residing with person with I/DD)	68	82.9
Caregiver has a chronic condition (% Yes)	40	48.7

hours per week were ordinal variables. Family size, number of people requiring care and age were continuous variables. Age was computed from the actual year of birth of the caregiver and person with I/DD respectively.

Outcome variables

To address the first research question, we examined participant self-reported data on utilization of health care services (i.e., having a primary care physician [PCP], having had a routine PCP visit in the past year, emergency department use, urgent care use, and type of insurance) over the 12 months preceding the program and again after they completed the program. Previous research has shown these health use indicators are associated with caregiver well-being (Hopps et al., 2017; Shaffer & Nightingale, 2020). To address the second research question, four distinct indicators of caregiver well-being and perceptions of global FQOL were analyzed. These indicators included *depression* (PHQ-9), *QOL* of caregiver (BREF-QOL), *stress* (PSS-10), *burden* (ZBI-12), *satisfaction with health* (BREF-QOL), and perceptions of global FQOL (FQOLS-2006). These measures were selected based on past research indicating that caregiving has a negative effect on mental health and wellbeing, resulting in caregiver burden that influences the health status of the caregiver and their QOL (Ehsan et al., 2018).

Patient health questionnaire (PHQ9)

The 9-item depression module of the PHQ was used to assess the mental health of the participants (Kroenke et al., 2001). The PHQ-9 items correspond to the nine DSM-IV criteria for depression and each was scored as 0 (not at all) to 3 (nearly every day). Scores ranging from 0–4 are considered normal, 5–9 indicates mild depression, 10–14 indicates moderate depression, 15–19 indicates moderately severe depression, and 20–27 indicates severe depression. Studies demonstrate that the PHQ-9 is sensitive to screen for depression among aging family caregivers of people with diverse conditions including I/DD (Willner et al., 2020). The tool had good internal consistency for this study (Cronbach's $\alpha = .85$).

World Health Organization's quality of life scale- brief (BREF-QOL)

Caregiver satisfaction with personal health and quality of life were measured using two items from the BREFQOL (Skevington et al., 2004). These two items on the WHOQOL-BREF are reported separately from the remaining 24 items that measure the four domains of quality of life. These self-reports are often not combined with the domains and are presented independently from the domains. Caregivers rated their satisfaction with health using a 5-point scale (5 = very satisfied, 1 = very dissatisfied), and their overall quality of life (QOL) using a 5-point scale (5 = excellent, 1 = poor). The BREF-QOL is reported to be valid and robust for testing factors that affect QOL of people with I/DD and aging caregivers (Rosén et al., 2020).

Perceived stress scale (PSS-10)

The 10-item PSS is designed to measure the degree to which life situations are appraised as stressful by an individual in the past month (Cohen et al., 1994). The 10 items were rated using a 5-point scale ranging from 0 for never to 4 for very often. Six items were reverse coded before using the items to compute a total score where higher scores indicated greater stress. Scores ≤ 13 were indicative of low stress, 14–26 indicated moderate stress and 27–40 indicated high stress. Research indicated that the PSS-10 is a reliable and valid way to measure family caregivers' stress in various contexts (González-Ramírez et al., 2013; Haley et al., 2020). The tool had excellent internal consistency (Cronbach's α = .90).

Zarit Burden Interview (ZBI)

The 12-item ZBI was used to measure caregiving burden in this study (Bédard et al., 2001). Each item was measured using a Likert scale ranging from 0 (never) to 4 (nearly always), with higher scores indicating greater burden. Scores ranging from 0–10 indicate low burden, 10–20 moderate burden, and scores >20 indicate high burden. Previous research indicated that the ZBI-12 can distinguish between low and high burden among older caregivers in diverse cultural contexts (Gratão et al., 2019). The tool had excellent internal consistency for the study population (Cronbach's α = .91).

Family quality of life scale- version 2006 (FQOLS-2006)

FQOL was measured using the mean score from two questions "Overall how would you describe your family's quality of life?" (5 = very good to 1 = very poor) and "Overall, how satisfied are you with your family's quality of life?" (5 = very satisfied to 1= very dissatisfied; Brown et al., 2006). These two questions are separate from the remaining items on the scale and are used to obtain a global perception of the FQOL and satisfaction with FQOL. They are reported independently and have been used without reporting on the domains that measure FQOL (Samuel et al., 2012). Higher scores indicated better FQOL. The FQOLS-2006 has been found to have good reliability and validity when used with caregivers of individuals with I/DD across the lifespan (Isaacs et al., 2012). The internal consistency of the 2-item subscale was good (Cronbach's α = .89).

Data analysis

Data were analyzed using IBM-SPSS version 26.0. Prior to beginning analyses, the data from collected surveys were reviewed to delete duplicate entries and those missing more that 50% of values. Descriptive statistics were used to provide means, standard deviations, and range of scores for each variable. Frequency distributions were used to describe the sample and provide a profile of the participants caring for adults with I/DD. Chi-square tests for independence and dependent sample *t*-tests were used to address the study questions. Cramer's V tests were used to assess the effect size of the significant relationships. All assumptions of normality were met and decisions on the statistical significance of the inferential statistical tests were made using a criterion alpha level of .05.

Findings

Most caregivers were female (84%), White (77%), married (74%), and ranged in age from 54 to 86 years (*M* = 65.1 years, *SD* = 6.6). Most caregivers were mothers (74%) with a college degree (72%) and a household income of $60,000 or more (61%). Fewer than half (34%) of the participants were employed. About 46% of the participants reported that they were providing care to more than one person in the family. Almost half (49%) of the participants reported having a chronic health condition. Most (83%) caregivers lived with their family members with I/DD, and 63% reported that they devoted over 20 hours to providing care per week (Table 2).

The mean age of the family members with disabilities was 33.1 years (*SD* = 12.2). The most commonly reported primary diagnosis was autism spectrum disorder (ASD; 64%). The most frequently reported associated problems were mood/anxiety problems (70%), behavior problems (63%), speech/language difficulties (56%), and gastro-intestinal problems (40%, data not shown in Tables).

Change in use of health care utilization

The most used medical insurance was private insurance (72%), followed by Medicare (42%), marketplace insurance (7%), and Medicaid (6%). At posttest, a significant increase from 6% to 17% was found for those who had Medicaid ($\chi^2 = 4.82$, $p = .03$; Table 3). Significantly fewer caregivers reported that they visited their PCP at least once over the past year from pretest to posttest (χ2 = 5.50, $p = 0.02$).

Change in caregiver well-being

Depression

All participants in this study reported having mild depression (PHQ-9 scores ranged from 5 to 9). The slight decrease from the start (*M* = 6.99, *SD* = 5.39) to the end of the study (*M* = 5.54, *SD* = 4.97) was statistically significant ($t = -3.54$, $p < .001$). This finding provided evidence that participants experienced less depression following completion of the intervention.

Stress

Before the study, caregivers, on average, reported moderate levels of stress (*M* = 22.49, *SD* = 4.48). After participating in the program, participants reported a statistically significant 2-point decrease in their stress level (*M* = 20.86, *SD* = 4.39; $t = -4.21$, $p < .001$). This result indicated that following the intervention, participants had significantly less stress.

Table 3. Impact of program on caregiver health and well-being.

Outcomes		Pre-test (n = 82)		Posttest (n = 82)		Group difference		Effect size
Health utilization		*N*	%	*N*	%	χ^2	*p*	*Cramer's V*
Has a primary care physician		75	91.5	77	93.9	.36	.55	
PCP visit in past year		73	98.6	69	89.9	5.50	.02	.19
ER use in past year								
None		66	81.5	71	86.6	2.93	.57	
1 time		9	11.1	7	8.5			
2–3 times		5	6.2	3	3.7			
>4 times		1	1.2	1	1.2			
Urgent care in past year								
None		58	70.7	64	78.0	1.96	.74	
Once		16	19.5	12	14.6			
2–3 times		6	7.3	5	6.1			
>4 times		2	2.4	1	1.2			
Type of insurance*								
Private		59	72.0	53	64.6	1.01	.31	
Medicare		34	41.5	36	43.9	.10	.75	
Marketplace		6	7.3	6	7.3	.00	1.0	
Medicaid		5	6.1	14	17.1	4.82	.03	.17
No insurance		4	4.9	1	1.2	1.86	.17	
Well-being indicators	*Min-Max*	*M*	*SD*	*M*	*SD*	*t*	*p*	*Cohen's d*
Depression	0-24	6.99	5.39	5.54	4.97	−3.54	<.001	−.39
Stress	12-34	22.49	4.48	20.86	4.39	−4.21	<.001	−.47
Burden	12-59	34.69	10.03	30.64	9.07	−5.91	<.001	−.66
QOL	1-5	3.57	0.93	3.73	0.92	1.81	.07	.20
Health satisfaction	1-5	3.20	1.05	3.43	1.16	2.10	.04	.23
FQOL	1-5	3.33	0.90	3.60	.95	3.56	<.001	.39

*Each participant could choose >1 category as they could have >1 type of insurance.

Burden

Before participating in the study, the caregivers reported a mean score of 34.69 (*SD* = 10.03). After participating in the study, caregiver burden decreased by about four points (*M* = 30.64, *SD* = 9.27). This difference was statistically significant ($t = -5.91$, $p < .001$), indicating burden had decreased following the intervention.

Quality of life

A slight improvement was noted in the caregivers' QOL from 3.57 (*SD* = .93) to 3.73 (*SD* =.92). The difference was not statistically significant, indicating the increase was not substantial. Satisfaction with personal health also significantly improved from 3.20 (*SD* = 1.05) to 3.43 (*SD* = 1.16) after participating in the study ($t = 2.10$, $p = .004$). This finding provided support that participants were more satisfied with their health following the intervention.

Global family quality of life

Global FQOL score increased from pretest (*M* = 3.33, *SD* = .90) to posttest (*M* = 3.60, *SD* = .95). This change was found to be statistically significant ($t = 3.56$, $p < .001$), indicating that FQOL increased following participation in the intervention.

In summary, decreased depression, stress, and burden, along with increases in QOL, satisfaction with health provide support that participation in MI-OCEAN intervention had a positive effect on caregiver's well-being. In addition, positive outcomes on global FQOL indicated the family's quality of life had improved after participating in the intervention.

Discussion

The purpose of this study was to describe how older caregivers of adults with I/DD benefited from participating in a peer mediated intervention tailored to the caregiving needs of individual families using the FQOL framework. Each family was assigned to an FSN who helped the family members develop an individualized action plan with three goals that aligned with the FQOL domains of highest importance. Most participants identified the health of the family to be one of the most important FQOL domains and were provided with informational support on strategies to improve their physical and mental health. All participants were encouraged to make future plans to care for their adult child with I/DD and provided with practical support to navigate complex systems of care.

The two significant findings in terms of health care utilization were increase in the use of Medicaid and reduced PCP visits at posttest. The informational and practical support provided in the MI-OCEAN appeared to be effective in educating families on qualifications for different types of insurance with many applying for Medicaid following the intervention. Past research has documented confusion regarding Medicaid among patients and their caregivers (McCullough & Dalstrom, 2018; Von Batten, 2019). The reduction in PCP visits during the past year could be attributable to the COVID-19 pandemic. Many families, including both caregivers and their family members with I/DD, were impacted by major changes in routine and availability of resources and services. Service navigation challenges among adults with I/DDs and their caregivers are well-documented (Marsack-Topolewski, 2020), with the pandemic creating more challenges to access and navigate services (Annaswamy et al., 2020; Cochran, 2020; Lake et al., 2021).

Geriatric social workers and other providers working with older caregivers and adults with I/DD should be sensitive to the myriad of challenges faced by families in finding, securing, and accessing services. Practitioners and policy makers should also be cognizant of service navigation challenges, whether due to the pandemic or any other reason, as they seek to help families connect with and access services in a streamlined fashion. As both caregivers and individuals with I/DD simultaneously age, their medical needs will change. Social workers and other health professionals should also be aware of the continuum of needs that families experience during transitional stages in life (e.g., health declines, need for different services, transportation). These changes may be better navigated with the assistance and support of an FSN. Social workers should maintain a keen eye to recognize when older caregivers need additional support and provide ease of entry to establish a partnership with an FSN.

Except for caregiver QOL, significant improvement was found in the other five indicators of health and well-being. The study findings imply that peer mediated family support programs can reduce caregiver stress, burden, depression, and improve satisfaction with health and FQOL. The stability of QOL ratings from past research can explain in part the lack of change in this study (Atkinson, 1982; Hinz et al., 2021). Despite the pandemic, it is surprising that QOL remained consistent.

The improvements in five of the six objective indicators of caregiver well-being and health align with past findings in aging research, demonstrating that systems navigation training programs can be instrumental in improving caregiver and family well-being (Bernstein et al., 2020; Funk, 2019). Peer mentorship models can promote self-actualization, advocacy skills, and reduce isolation for older caregivers supporting adults with I/DD (Smith et al., 2018). When a mentor and the mentee share similar life experiences, research has shown improvements in the perspective of the individual receiving the support, experiencing multiple life challenges for example people with cancer, dementia, heart disease, and mental illness (Greenwood et al., 2013; Taylor et al., 2017). The FSN, like a mentor who has experienced similar life experiences with the mentee, is uniquely positioned to share information and provide support to older caregivers with caring for their child with I/DD. Therefore, geriatric social workers, other practitioners, and policy makers should recognize the merit of peer mentorship. A need exists to coordinate efforts to establish program development (where they do not exist) and encourage older caregivers to participate in peer mentored family support programs. Geriatric social workers are well positioned to leverage community partnerships and relationships to establish peer mentorship models.

Limitations

There are limitations to be considered when interpreting the results from a study without a control group or randomization. A limitation was the homogeneity in the sample as most participants were mothers, Caucasian, and married. As a result, they may be more connected to the service system with the time, interest, and resources to participate in this web-based research study. Caregivers who are disconnected from service systems, and from lower socioeconomic groups may be overwhelmed by their caregiving responsibilities and not have the ability to access the MI-OCEAN program and may have been inadvertently excluded from the study. Future research should focus on recruiting a larger, more heterogeneous sample to allow generalization to more caregivers in the state.

Focusing the study on one state could also be a limitation, with a recommendation to extend the study to other states to determine if the program is successful in helping aging caregivers manage their caregiving responsibilities. The lack of a control group and follow-up after exiting the study can limit the ability to determine whether the observed improvements were due to the intervention. Contacting participants and asking them to complete the posttest a second time could provide information on the lasting effects of participating in the study. Longitudinal analyses can provide a richer understanding on how aging caregivers contend with the effects of aging on their own health alongside their lifelong caregiving responsibilities, and how that influences their ability to continue caregiving.

Despite these limitations, this study informs knowledge gaps in the literature on older caregivers of adults with I/DD. The outcomes focus on the health and well-being of the caregiver, which is often affected by age and caregiving responsibilities. Future research is needed to examine the long-term impact of family support programs in improving the health and well-being of aging caregivers.

Conclusion

The preliminary findings on the MI-OCEAN indicate that a peer-mediated systems navigation program can help older caregivers get connected with the necessary services to plan for the future of their adult children with I/DD while managing their personal health and well-being. The goal of the program grounded in the FQOL framework was to extend a family support program developed for caregivers of young children to the older families caring for adults with I/DD moving across the life span. Study findings also indicate the need to expand this program to include caregivers of adolescents and emerging adults to prepare them for their future by learning how to navigate adult services for people with I/DD.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the Michigan Health Endowment Fund under Grant # R-1807-143067.

Notes on contributors

Sharon Milberger, ScD is the Director of the Michigan Developmental Disabilities Institute, Wayne State University, Detroit, MI.

Christina Marsack-Topolewski, PhD, LMSW is an Associate Professor in the School of Social Work in Eastern Michigan University, Ypsilanti, MI.

Elizabeth Janks, MSW is the Associate Director of Training and Community Support at the Michigan Developmental Disabilities Institute at Wayne State University, Detroit, MI.

Nia Anderson, MSW is a Research Assistant at the Michigan Developmental Disabilities Institute at Wayne State University, Detroit, MI.

Michael Bray, EdS is the Director Associate Director for Dissemination and Technology, Michigan Developmental Disabilities Institute at Wayne State University, Detroit, MI.

Preethy S. Samuel, PhD is an Associate Professor of Occupational Therapy, Department of Health Care Sciences in the Eugene Applebaum College of Pharmacy & Health Sciences, and an Adjunct Faculty of the Michigan Developmental Disabilities Institute, Wayne State University, Detroit, MI.

References

AARP and National Alliance for Caregiving. (2020, May). *Caregiving in the United States 2020*. AARP. https://doi.org/10.26419/ppi.00103.001.

Annaswamy, T. M., Verduzco-Gutierrez, M., & Frieden, L. (2020). Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond. *Disability and Health Journal*, *13*(4), 100973. https://doi.org/10.1016/j.dhjo.2020.100973

Atkinson, T. (1982). The stability and validity of quality of life measures. *Social Indicators Research*, *10*(2), 113–132. https://doi.org/10.1007/BF00302506

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden interview: A new short version and screening version. *The Gerontologist*, *41*(5), 652–657. https://doi.org/10.1093/geront/41.5.652

Bernstein, A., Merrilees, J., Dulaney, S., Harrison, K. L., Chiong, W., Ong, P., Heunis, J., Choi, J., Walker, R., Feuer, J. E., Lee, K., Dohan, D., Bonasera, S. J., Miller, B. L., & Possin, K. L. (2020). Using care navigation to address caregiver burden in dementia: A qualitative case study analysis. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *6*(1), e12010. https://doi.org/10.1002/trc2.12010

Berrick, J. D., Young, E. W., Cohen, E., & Anthony, E. (2011). 'I am the face of success': Peer mentors in child welfare. *Child & Family Social Work*, *16*(2), 179–191. https://doi.org/10.1111/j.1365-2206.2010.00730.x

Brown, I., Brown, R. I., Baum, N. T., Isaacs, B. J., Myerscough, T., Neikrug, S., Roth, D., Shearer, J., & Wang, M. (2006). *Family quality of life survey: Main caregivers of people with intellectual or developmental disabilities*. Surrey Place Centre.

Cochran, A. L. (2020). Impacts of COVID-19 on access to transportation for people with disabilities. *Transportation Research Interdisciplinary Perspectives*, *8*, 100263. https://doi.org/10.1016/j.trip.2020.100263

Cohen, S., Kamarck, T., & Mermelstein, R. (1994). Perceived stress scale. *Measuring Stress: A Guide for Health and Social Scientists*, *10*(2), 1–2.

Cullen, L. A., & Barlow, J. H. (2004). A training and support programme for caregivers of children with disabilities: An exploratory study. *Patient Education and Counseling*, *55*(2), 203–209. https://doi.org/10.1016/j.pec.2003.09.004

Ehsan, N., Johar, N., Saleem, T., Khan, M. A., & Ghauri, S. (2018). Negative repercussions of caregiving burden: Poor psychological well-being and depression. *Pakistan Journal of Medical Sciences*, *34*(6), 1452. https://doi.org/10.12669/pjms.346.15915

Fifield, J. (2016). *What happens to developmentally disabled as parents age, die?* The Pew Charitable Trusts. Retrieved November 11, 2021, from https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2016/08/10/what-happens-to-developmentally-disabled-as-parents-age-die

Funk, L. M. (2019). Relieving the burden of navigating health and social services for older adults and caregivers. *IRPP Study*, *73*.

González-Ramírez, M. T., Rodríguez-Ayán, M. N., & Hernández, R. L. (2013). The perceived stress scale (PSS): Normative data and factor structure for a large-scale sample in Mexico. *The Spanish Journal of Psychology*, *16*, E47. https://doi.org/10.1017/sjp.2013.35

Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., de Oliviera, N. A., Terassi, M., & Pavarini, S. C. I. (2019). Brief version of Zarit Burden interview (ZBI) for burden assessment in older caregivers. *Dementia & Neuropsychologia*, *13*(1), 122–129. https://doi.org/10.1590/1980-57642018dn13-010015

Greenwood, N., Habibi, R., Mackenzie, A., Drennan, V., & Easton, N. (2013). Peer support for carers: A qualitative investigation of the experiences of carers and peer volunteers. *American Journal of Alzheimer's Disease and Other Dementias*, *28*(6), 617–626. https://doi.org/10.1177/1533317513494449

Haley, W. E., Roth, D. L., Sheehan, O. C., Rhodes, J. D., Huang, J., Blinka, M. D., & Howard, V. J. (2020). Effects of transitions to family caregiving on well-being: A longitudinal population-based study. *Journal of the American Geriatrics Society*, *68*(12), 2839–2846. https://doi.org/10.1111/jgs.16778

Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, *44*(3), 189–202. https://doi.org/10.1352/0047-6765(2006)44[189:SACAAW]2.0.CO;2

Heller, T., & Schindler, A. (2009). Family support interventions for families of adults with intellectual and developmental disabilities. *International Review of Research in Mental Retardation*, *37*, 299–332. https://doi.org/10.1016/S0074-7750(09)37009-3

Hinz, A., Schulte, T., Rassler, J., Zenger, M., & Geue, K. (2021). Temporal stability of quality of life assessments in cancer patients. *Scientific Reports*, *11*(1), 1–6. https://doi.org/10.1038/s41598-021-84681-0

Hopps, M., Iadeluca, L., McDonald, M., & Makinson, G. T. (2017). The burden of family caregiving in the United States: Work productivity, health care resource utilization, and mental health among employed adults. *Journal of Multidisciplinary Healthcare*, *10*, 437–444. https://doi.org/10.2147/JMDH.S135372

Isaacs, B. J., Brown, I., Brown, R. I., Baum, N., Myerscough, T., Neikrug, S., Roth, D., Shearer, J., & Wang, M. (2007). The international family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(3), 177–185. https://doi.org/10.1111/j.1741-1130.2007.00116.x

Isaacs, B., Wang, M., Samuel, P., Ajuwon, P., Baum, N., Edwards, M., & Rillotta, F. (2012). Testing the factor structure of the Family Quality of Life Survey - 2006. *Journal of Intellectual Disability Research*, *56*(1), 17–29. https://doi.org/10.1111/j.1365-2788.2011.01392.x

Isaacs, B., Wang, M., Samuel, P., Ajuwon, P., Baum, N., Edwards, M., & Rillotta, F. (2012). Testing the factor structure of the Family quality of life survey–2006. *Journal of Intellectual Disability Research*, *56*(1), 17–29. https://doi.org/10.1111/j.1365-2788.2011.01392.x

Jamison, J. M., Fourie, E., Siper, P. M., Trelles, M. P., George-Jones, J., Buxbaum Grice, A., Kolevzon, A., Holl, E., Shaoul, J., Hernandez, B., Mitchell, L., McKay, M. M., Buxbaum, J. D., & Kolevzon, A. (2017). Examining the efficacy of a family peer advocate model for black and Hispanic caregivers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(5), 1314–1322. https://doi.org/10.1007/s10803-017-3045-0

Javalkar, K., Rak, E., Phillip, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of caregiver burden among mothers of children with chronic conditions. *Children*, *4*(5), 1–10. https://doi.org/10.3390/children4050039

Jokinen, N. S., & Brown, R. I. (2005). Family quality of life from the perspective of aging parents. *Journal of Intellectual Disability Research*, *49*(10), 789–793. https://doi.org/10.1111/j.1365-2788.2005.00753.x

Joo, J. H., Bone, L., Forte, J., Kirley, E., Lynch, T., & Aboumatar, H. (2022). The benefits and challenges of established peer support programmes for patients, informal caregivers, and healthcare providers. *Family Practice* English doi:10.1093/fampra/cmac004 . https://pubmed.ncbi.nlm.nih.gov/35104847/ It is an ePub published online so there is no issue number available yet.

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Lake, J. K., Jachyra, P., Volpe, T., Lunsky, Y., Magnacca, C., Marcinkiewicz, A., & Hamdani, Y. (2021). The wellbeing and mental health care experiences of adults with intellectual and developmental disabilities during COVID-19. *Journal of Mental Health Research in Intellectual Disabilities*, *14*(3), 285–300. https://doi.org/10.1018/19315864.2021.1892890

Lee, C., & Burke, M. M. (2020). Future planning among families of individuals with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(2), 94–107. https://doi.org/10.1111/jppi.12324

Marsack-Topolewski, C. N. (2020). Quality of life among compound caregivers and noncompound caregivers of adults with autism. *Journal of Gerontological Social Work*, *63*(5), 379–391. https://doi.org/10.1080/01634372.2020.1765063

McCullough, K., & Dalstrom, M. (2018). I am insured but how do I use my coverage: Lessons from the front lines of medicaid reform. *Public Health Nursing*, *35*(6), 568–573. https://doi.org/10.1111/phn.12525

Owen, A., Stober, K., Crabb, C., Mahar, E., & Heller, T. (2021). Training professionals to facilitate future planning for aging caregivers: Exploratory results from a multistate intervention. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(2), 131–140. https://doi.org/10.1111/jppi.12362

Perkins, E. A. (2010). The compound caregiver: A case study in multiple caregiving roles. *Clinical Gerontologist*, *33*(3), 248–254. https://doi.org/10.1080/07317111003773619

Rone-Adams, S. A., Stern, D., & Walker, V. (2004). Stress and compliance with a home exercise program among caregivers of children with disabilities. *Pediatric Physical Therapy*, *16*(3), 140–148. https://doi.org/10.1097/01.PEP.0000136006.13449.DC

Rosén, H., Ahlström, G., & Lexén, A. (2020). Psychometric properties of the WHOQOL-BREF among next of kin to older persons in nursing homes. *Health and Quality of Life Outcomes*, *18*(1), 103. https://doi.org/10.1186/s12955-020-01345-9

Samuel, P. S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research*, *56*(1), 1–16. https://doi.org/10.1111/j.1365-2788.2011.01486.x

Samuel, P. S., Wright, K., Marsack-Topolewski, C., & DiZazzo-Miller, R. (2021). When more is too much: Compound caregiving, barriers to services, and service support for older families of people with disabilities. *Families in Society*, *103*(2), 180–193. https://doi.org/10.1177/10443894211048456

Shaffer, K. M., & Nightingale, C. L. (2020). Comparison of healthcare utilization between informal caregivers and non-caregivers: An analysis of the health information national trends survey. *Journal of Aging and Health*, *32*(5–6), 453–461. https://doi.org/10.1177/0898264319830262

Skevington, S. M., Lotfy, M., O'Connell, K. A., & WHOQOL Group. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *13*(2), 299–310. https://doi.org/10.1023/B:QURE.0000018486.91360.00

Smith, R., Drennan, V., Mackenzie, A., & Greenwood, N. (2018). The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Archives of Gerontology and Geriatrics*, *76*, 188–195. https://doi.org/10.1016/j.archger.2018.03.005

Sung, M., & Park, J. (2012). The effects of a family support program including respite care on parenting stress and family quality of life perceived by primary caregivers of children with disabilities in Korea. *International Journal of Special Education*, *27*(3), 188–198.

Tanis, E. S., Lulinski, A., Wu, J., Braddock, D., & Hemp, R. (2021). *The state of the States in intellectual and developmental disabilities*. Department of Psychiatry, University of Colorado.

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training parents of youth with autism spectrum disorder to advocate for adult disability services: Results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders*, *47*(3), 846–857. https://doi.org/10.1007/s10803-016-2994-z

Von Batten, K. (2019). *Patients' Confusion Relating to the Center for Medicare & Medicaid Services (CMS) and Private Insurance Preventive Care and Wellness Examination Guidance: A Preliminary Study*. Available at SSRN 3392433.

Wang, F., Marsack-Topolewski, C. N., DiZazzo-Miller, R., & Samuel, P. S. (2022). Health of aging families: Comparing compound and noncompound caregivers. *Journal of Gerontological Social Work*, *65*(3), 290–304. https://doi.org/10.1080/01634372.2021.1963024

Whitley, D. M., & Fuller-Thomson, E. (2018). Latino solo grandparents raising grandchildren: Health risks and behaviors. *Hispanic Health Care International*, *16*(1), 11–19. https://doi.org/10.1177/1540415318757219

Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G. H., Langdon, P. E., Clifford, C., Cooper, V., Watkins, A., Hiles, S., & Cooper, V. (2020). Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *33*(6), 1523–1533. https://doi.org/10.1111/jar.12811

Zuna, N. I., Turnbull, A., & Summers, J. A. (2009). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 25–31. https://doi.org/10.1111/j.1741-1130.2008.00199.x

Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T., Collumbien, M., & Bernays, S. (2019). A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. *Child: Care, Health and Development*, *45*(1), 45–53. https://doi.org/10.1111/cch.12618