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Evaluation of peer-mediated systems navigation for ageing families of individuals with developmental disabilities

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Abstract

Background As individuals with intellectual and developmental disabilities (I/DD) age, services often diminish, with many family caregivers experiencing challenges finding and navigating services. The purpose of this study was to examine the benefits of a state-wide family support project for ageing caregivers (50+) of adults with I/DD in accessing and using services.

Method A one-group pre-test–post-test design was used to determine if participation in the MI-OCEAN intervention grounded in the Family Quality of Life (FQOL) theory reduced ageing caregivers' (n = 82) perceptions of barriers to accessing, using and needing formal services.

Results After participating in the study, there was a reduction in reported barriers to accessing services. There was also greater use and reduced need for 10 of the 23 listed formal services.

Conclusions Findings indicate that a peer-mediated intervention grounded in FQOL theory can be beneficial in empowering ageing caregivers by reducing perceived barriers to accessing services and increasing their use of advocacy and support services.

Keywords adults with intellectual disabilities, ageing family caregivers, barriers, peer mentors, systems navigation

Background

Approximately 5.1 million children and 2.1 million adults in the USA have intellectual and developmental disabilities (I/DD; Tanis 2020). While most (72%) individuals with I/DD live with their families, 24% are living with family caregivers aged 60 or more (Tanis 2020; Larson *et al*. 2021). These families comprise an informal system of residential care that is five times greater than the formal out-of-home residential care system (Braddock *et al*. 2017). In addition, 78% of American adults with disabilities who receive long-term care at home get all their care exclusively from unpaid family members and friends (Heller & Schindler 2009). Less than 7% of national expenditures for people with I/DD are directed at family support, suggesting that caregivers are scrambling to access the meagre home and community-based supports (Braddock *et al*. 2017). In the remainder of the paper, the term caregiver(s) refers to unpaid, informal family caregiver(s), such as a parent, spouse, sibling or other relatives.

Caregiving can be rewarding and can be linked with many positive changes in family members (Waizbard-Bartov *et al*. 2019; Marsack-Topolewski *et al*. 2021).

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Caregiving duties often arise unexpectedly, demanding quick responses from family members who often assume their caregiving life roles without any formal training (Schulz *et al.* 2020). However, given the longer life expectancy and the limited availability of formal social supports, caregiving can seem enduring and burdensome (Heller & Schindler 2009). Caregiving requires the collective effort of each family member, requiring adaptation and role shifts that influence the domains of individual-level and family-level quality of life (QOL; Scharlach *et al.* 2006).

The Family Quality of Life (FQOL) theory offers a strengths-based approach to understand strengths, challenges and desires of caregiving families (Samuel *et al.* 2012). The FQOL approach represents a paradigm shift in disability service provision, moving from fixing to supporting, deficits to strengths and individual to family as the focus of support. FQOL research has primarily focused on young children with I/DD, with a few exceptions that included ageing families (Jokinen & Brown 2005; Wang *et al.* 2022). 'Support from services' is one of the nine core domains of the international FQOL framework that was adopted for this study (Brown *et al.* 2006; Isaacs *et al.* 2007).

Service needs for individuals with I/DD vary depending on several factors (e.g. type and severity of disability) and can change over the lifespan (Bowers 2019). Most families of individuals with I/DD can attest to difficulties staying informed regarding availability of resources and support services needed by the caregiver and care recipient, particularly as age increases (Gilson *et al.* 2017). Ageing families of adults with I/DD face a variety of barriers when attempting to access services, such as availability, affordability and acceptability (Marsack-Topolewski & Weisz 2020). Systems are often designed around fiscal advantages rather than user-friendliness of consumers of health and disability supports.

Family navigation services provided by peers appear to be a promising method of supporting families to obtain needed services and supports from a complex web of health care and disability systems (Markoulakis *et al.* 2019). Despite the recognition of service navigation challenges faced by families of adults with I/DD, little is known about interventions that empower ageing caregivers to navigate complex systems of care. Most research has focused on psychoeducational support and training of parents of young children and youth with autism (Feinberg *et al.* 2016; Derguy *et al.* 2017; Taylor *et al.* 2017; Broder-Fingert *et al.* 2018; DaWalt *et al.* 2018). Peer-mediated navigator programmes can empower caregivers by providing information and skills to prevent families from reaching crisis points during life transitions (Heller & Caldwell 2006; Berrick *et al.* 2011; Jamison *et al.* 2017). For example, Feinberg *et al.* (2016) reported that family navigation can reduce diagnostic wait time for children with autism spectrum disorder (ASD). Family navigation mediated by peers also can reduce disparities in accessing care (Broder-Fingert *et al.* 2018; Son *et al.* 2020). A systematic review of studies focusing on peer support for parents of children with disabilities demonstrated that parents believed that there was a benefit to using a peer support model (Shilling *et al.* 2013). These programmes often engage peer mentors who use personal and professional life experiences to build rapport and provide family members hope and tools for a better future (Smith *et al.* 2018). Although support programmes can improve family well-being, most are focused on children or youth (Sung & Park 2012; DaWalt *et al.* 2018; Zuurmond *et al.* 2019).

Lee & Burke (2020), in a systematic review, asserted that ageing caregivers experience many challenges to future planning despite acknowledging the need to plan because their adult children with I/DD were very likely to outlive them. The 'Future is Now' programme is an example of a manualised curriculum using peer support with ageing families of adults with I/DD to encourage future planning but does not address advocacy and systems navigation. However, published evidence on its use and efficacy is limited (Heller & Caldwell 2006; DeBrine *et al.* 2009). To address the needs of XX's ageing families, the XX **O**lder **C**aregivers of **E**merging **A**dults with Autism and **N**eurodevelopmental Disabilities (MI-OCEAN), a family support project, was developed. The intervention evolved out of a federally funded Project of National Significance in XX designed to empower low-income parents of racial/ethnic minorities caring for children with I/DD (Heller & Schindler 2009).

The purpose of this study was to examine if a state-wide family support project (MI-OCEAN) for older caregivers (50+) of adults with I/DD could reduce their perception of barriers to accessing, using and needing services. As family navigation service programmes develop, understanding their unique contribution in family outcome measurement is essential (Markoulakis *et al.* 2019). While navigation service programmes have been found to be effective in addressing barriers to care and increased use of services (Dohan & Schrag 2005; Valaitis *et al.* 2017; McCrossin *et al.* 2022), none of the published studies directly addressed the use of advocacy to empower ageing family members in accessing services needed by their adult care recipients with I/DD. To address this need, this study was guided by the research question, 'Will there be a reduction in perceived barriers to accessing, using and needing formal supports for caregivers of adults with I/DD after participating in MI-OCEAN?' Based on a review of the literature on the use of caregiver training and advocacy to help improve access to services for their children with I/DD and adults with dementia (Smith *et al.* 2018; Dababnah *et al.* 2021; Feinberg *et al.* 2021), the following hypotheses were tested:

1. A reduction in perceived barriers to accessing health and disability services will be noted after study participation.
2. Increased use and reduced need for some formal services will be noted after study participation.

Method

Research design

As part of a larger study, this research used a one-group pre-test–post-test design to evaluate participation outcomes (Milberger *et al.* 2022). As this design does not use a comparison group, the researchers cannot conclude that changes in participants' use and need for services were due to the intervention (Chiang *et al.* 2017). Approval was obtained from Wayne State University's Institutional Review Board (IRB) before conducting the study.

Recruitment

Recruitment efforts initiated in 2019 occurred through email listservs, social media and partnerships with local organisations connected with ageing and I/DD networks. Snowball sampling was also used with the recruited participants. The COVID-19 pandemic that occurred during the project limited face-to-face meetings, with recruitment and intervention continuing via phone and virtual meetings.

Participants

Caregivers in the study met the inclusion criteria: at least 50 years old, providing care for an adult family member (18+) with I/DD, able to speak and comprehend English or Spanish and currently residing in the state of Michigan. Caregivers in this study can be considered as relatively younger 'older caregivers', mainly between the ages of 60–69 years. Categorising caregivers as older is a difficult task as ageing groups are changing. The needs of older-aged families (i.e. with care recipients aged 40+), and particularly those who have remained outside the service system, are likely to differ especially as both encounter health challenges. Although more than 50% of caregivers are over the age of 50 in the USA, most services and support are devoted to young children with I/DD and their often-younger parents (American Association of Retired Persons & National Alliance for Caregiving 2020).

The Michigan Health Endowment Fund authorised funding for 100 ageing caregivers of adult family members with I/DD; therefore, only the first 100 volunteers who met the eligibility criteria and completed the pre-tests were recruited into the study. Eighty-two caregivers also completed the post-tests. All families who completed the pre-tests and the initial visit with their family support navigators (FSNs) received an informational resource packet. Four of the 18 who did not complete the post-tests dropped out of the study without implementing an Individualised Action Plan (IAP) developed with their FSN. Reasons for dropping out included difficult life circumstances such as unexpected illnesses or deaths in the family or having to move out of state. One family, for example, was under high stress during pandemic that the mother only wanted some resources and did not have the time to participate in the project. Comparative analyses summarised in Table 1 indicated no differences in demographic characteristics between participants and dropouts.

Participants received $20 and $30 gift cards upon completion of pre-test and post-test, respectively. The incremental increase at post-test was to encourage ongoing participation and study completion. The

Table 1 Participant characteristics

	All participants *n* **= 82**	**Dropouts** *n* **= 18**	**Group differences***
	% (*n*)	**% (*n*)**	χ^2
Gender			
Female	84.1 (69)	94.4 (17)	1.30
Living arrangements (% co-residing with person with I/DD)	82.9 (68)	83.3 (15)	0.00
Caregiver has a chronic condition (% yes)	48.7 (40)	50.0 (9)	0.01
Compound caregiving (% caregiving for more than 1 person)	46.3 (38)	33.3 (6)	1.01
Relationship to care recipient			
Mother	73.2 (60)	77.8 (14)	0.26
Father	14.6 (12)	5.6 (1)	
Sister	4.9 (4)	16.7 (3)	
Other (nephew, aunt, uncle etc.)	7.3 (6)	–	
Marital status			
Married or domestic partnership	74.4 (61)	61.1 (11)	0.31
Not married (widowed, divorced or separated)	4.9 (4)	38.9 (7)	
Single/never married	20.7 (17)	–	
Race†			
Caucasian/White	77.3 (68)	66.7 (12)	2.01
Black/African American	9.1 (8)	16.7 (3)	
Hispanic American	2.3 (2)	5.6 (1)	
Asian/Arabic/Pacific Islander	7.3 (6)	5.6 (2)	
Native American/Alaskan native	1.0 (1)	11.1 (2)	
Other/mixed race	2.3 (2)	–	
Education			
High school	14.6 (12)	16.7 (3)	0.86
Some college	14.6 (12)	22.2 (4)	
Bachelor's degree	29.3 (24)	33.3 (4)	
Graduate or higher	41.5 (34)	27.8 (7)	
Employment status			
Full-time paid work	23.2 (19)	27.8 (5)	2.71
Part-time paid work	11.0 (9)	22.2 (4)	
Retired	36.6 (30)	27.8 (5)	
Not working (e.g. homemaker, stay-at-home caregiver or disability)	26.8 (22)		
Unemployed/unable to work	2.4 (2)	22.2 (4)	
Annual household income			5.43
Below 30 000	11.7 (9)	33.3 (6)	
31 000–60 000	23.4 (18)	27.8 (5)	
61 000–90 000	36.4 (28)	16.7 (3)	
Above 91 000	28.6 (22)	22.2 (4)	
Missing	*5*		
Age of caregiver			
54 or below	3.7 (3)	5.6 (1)	1.19
55–59	22.0 (18)	11.1 (2)	
60–64	28.0 (23)	33.3 (6)	
65–69	30.5 (25)	33.3 (6)	
70–74	9.8 (8)	16.7 (3)	
75 or more	6.1 (5)	–	
Age of person with I/DD			
19 or below	2.4 (2)	–	3.25
20–24	36.6 (30)	16.7 (3)	
25–29	20.7 (17)	27.8 (5)	
30–34	19.5 (16)	27.8 (5)	

Table 1. *(Continued)*

	All participants *n* = 82	Dropouts *n* = 18	Group differences*
35–39	8.5 (7)	–	
40–44	3.7 (3)	–	
45 or more	8.5 (7)	16.7 (5)	
	M (SD)	**M (SD)**	***t***
Family size			
Total number of family members (1–10)	3.99 (1.87)	3.50 (1.51)	1.04
Family members needing care (1–5)	1.72 (0.97)	1.53 (0.72)	0.76

*The two-tailed *P* values associated with the test statistic (χ^2 and *t* values) were above 0.05, indicating that there were no significant differences between the groups.

†Exceeds 100% because participants could select more than one response.

I/DD, intellectual and developmental disabilities.

amounts and timing of the incentives were approved by the funding agency and the local IRB.

Participants were predominantly female, White, college educated and married mothers with household incomes of $60 000 or more. Close to a third (34%) of the caregivers were employed and 46% were caregiving for more than one person in the family. Most were co-residing with the person with I/DD and spending over 20 h/week on caregiving (Table 1).

The median age of the caregivers was 63 years (M = 64.1, SD = 6.6, range 52 to 84), while the median age of the adult care recipient with I/DD was 27 years (M = 29.9, SD = 9.57, range 19 to 61). Commonly reported diagnoses were unspecified I/DD (*n* = 57, 69.5%), ASD (*n* = 50, 60.9%), epilepsy (*n* = 17, 20.7%), Down syndrome (*n* = 13, 15.9%) and cerebral palsy (*n* = 12, 14.6%). Among those who reported a diagnosis of ASD, the majority (54%) also reported an I/DD. The caregivers reported mood, behaviour, speech/language and gastrointestinal symptoms as common problems among their care recipients.

Intervention and procedures

This project emerged from two decades of work with locally under-resourced families of individuals with I/DD. Under-resourced is defined as the inability to access resources (e.g. funding, programming, support networks, physical assistance and communication technology) for themselves or their family members (Hunt *et al.* 2022). The programme was aligned with the Association for Children's Mental Health Program to ensure the expansion of their Person Support Person model in Michigan to address adult and ageing service systems. Past family support navigation programmes have demonstrated efficacy with similar populations as discussed earlier in this paper (i.e. DaWalt *et al.* 2018; Dababnah *et al.* 2021; Feinberg *et al.* 2021). The present study used an FSN model to assist caregivers in obtaining services for their care recipients.

Fourteen FSNs were hired to work as peer mentors. The FSNs had to be at least 60 years of age with cultural sensitivity and past experiences with navigating the health and disability service system in XX. They had the contextual understanding needed to assist ageing caregivers who were supporting and caring for an adult with I/DD. All FSNs completed a comprehensive 2-day training programme via the Zoom platform because they were located across the state. The training curriculum for FSNs was adapted from past intervention manuals that were developed and refined by stakeholders of three externally funded family support projects from 2003 to 2012 (see Table 2 for topics). The FSN training curriculum was grounded in the FQOL framework (Brown *et al.* 2006) to assist ageing caregivers in understanding key elements of service delivery, including obtaining and using services while transitioning across the lifespan. Modifications for the current project included adding information on

Table 2 Family support navigator training curriculum

Introduction	Project summary: project goal and objectives and 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	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 Centred Practices
Chapter 10	Developing the Individualised Action Plan
Chapter 11	Transition Planning and Fading
Chapter 12	Home Visiting, Safety and Confidentiality
Chapter 13	Grief & Loss

ageing related supports and services. Past projects focused on addressing needs of families with young children and lacked information on transition planning for post-secondary education, employment, housing and applying for benefits for which only adults with I/DD were eligible.

Following screening for eligibility and an intake process to determine the family's situation, level of need and current access to services, each caregiver was matched with an FSN in their region by the programme manager. Each caregiver received an email with a link to complete the pre-test online. The project evaluator used pre-test data to conduct a preliminary analysis and develop an individualised FQOL report. Each family's report included three domains considered to be most *important* to their FQOL, along with a graphical representation of ratings for the remaining five dimensions (*opportunity*, *initiative*, *attainment*, *stability* and *satisfaction*) in each of the nine FQOL domains (Brown *et al*. 2006). About 40% (n = 32) of the families identified the FQOL domain of 'support from services' to be one of their top three domains of importance to their overall FQOL. In comparison with the other nine domains, this domain ranked four after family, health and finances. The project manager reviewed the report and then forwarded it to the FSNs to share with their assigned caregivers. This evaluation process ensured confidentiality of the caregiver's pre-test responses to other constructs such as stress and burden. The FSNs used the FQOL report to guide the development of the IAP. Each family's IAP consisted of three goals (one long-term and two short-term), as well as networking strategies to access diverse services, and provided a roadmap for navigating service systems. The length of intervention for each family to achieve the goals varied, with progress evaluated every 6 months by the programme manager.

The programme manager convened 12 monthly group meetings (2 in-person and 10 virtual) of 1-h duration to facilitate interaction between the FSNs, participants and project staff. Monthly group meeting attendance varied from group to group, depending on the topic of discussion. Each session, comprising 15–30 people, included socialisation and structured learning opportunities to allow caregivers to practise their new skills to broker their individual service networks and support. Caregivers learned how to contact resource personnel and use the correct language to access information (e.g. asking for respite funding, instead of childcare).

Following programme completion, each caregiver was post-tested to measure changes that may have occurred from participating in the programme. The post-test was the same as the pre-test, except that demographic information was not obtained.

Measures

A web-based survey was created using the Qualtrics platform to gather information on socio-demographics of the caregiver and the care recipient requiring support, and the caregiving context using standardised measures of caregiver health and well-being (see Milberger *et al*. 2022 for more details on tool).

Study variables

Two questions on barriers from the international FQOL survey were used (Brown *et al*. 2006). Participants were asked if they faced barriers in accessing health care and disability services. Participants who answered 'yes' also answered an additional question on the types of barriers faced. Participants could select multiple options that described common barriers (e.g. long wait for services and problems with transportation).

Participants were also asked about the need for and use of 23 formal services with three responses: '*yes*, we currently have this support', 'we are in *need* of this support' or '*no*, we do not desire this support'. While the 23 items for formal services have not been studied for reliability and construct validity, these items were developed in consultation with professionals in the field (content validity) and have been used in previous research for caregivers of adults with I/DD (Marsack 2016).

Analyses

Data were analysed using IBM SPSS version 28.0. Prior to beginning analyses, data were screened for errors and duplicate entries. Variables of interest were summarised using frequency distributions and descriptive statistics. All assumptions of the inferential, nonparametric McNemar and McNemar–Bowker tests were met prior to beginning analysis. The McNemar–Bowker test, an extension of the McNemar test, compares changes with three possible outcomes from pre-test to post-test (Fagerland *et al*. 2017). Effect sizes were determined using Cramer's V, with results of 0.10 considered small, 0.30 were medium and 0.50 indicated a large effect (Ellis 2010). Decisions on the statistical significance were made using an alpha level of 0.05. Using *post hoc* G*Power 3.1 for two dependent tests, a sample of 82 participants with an alpha level of 0.05 and an effect size of 0.50 yielded a power of 0.88.

Findings

Barriers to accessing services

Among the 22 participants who indicated that they faced barriers in accessing health and disability-related services at pre-test, 14 continued to report barriers at post-test. The exact McNemar test indicated that this reduction was significant ($P = 0.03$; Table 3). An examination of the 10 listed barriers indicated a significant reduction in two: participants who reported that they did not know where to go for services ($P = 0.003$) and a long wait for services ($P = 0.004$). Of the 12 participants who reported not knowing where to go for services at pre-test, 8 continued to report this barrier at post-test. Similarly, 14 participants reported the barrier of long waiting periods to obtain services at pre-test compared with 3 at post-test ($P = 0.004$). The barrier, availability of services in the area, remained constant from pre-test to post-test. The Cramer's V values associated with barriers ranged from 0.12 (transportation) to 0.56 (overall question), indicating that the effect sizes were primarily medium to large.

Patterns of service use and need

After participating in the programme, caregivers were less likely to need 21 of the 23 services. The two services where the need increased were occupational therapy and adult day care. At post-test, participants reported increased use of 19 of the 23 services. The four services with decreased use were physical therapy, institutions, group homes and adult day care. The number of participants reporting that they did not need the 23 services at pre-test increased for 15 of the services at post-test, indicating that their need for these services had decreased. See Table 4 for comparisons of use, need and non-use of individual services.

The McNemar–Bowker test results indicated that the proportion of people using and needing services changed significantly for 10 of the 23 services (Table 4). Five services were related to caregiver advocacy ($P < 0.001$); disability-specific support groups ($P = 0.005$); and caregiver support groups at the community ($P = 0.001$), national ($P = 0.004$) and state ($P = 0.010$) levels. The remaining were related to services needed for the person with disability: counselling ($P = 0.006$), physical therapy

Table 3 McNemar's test: change in perception of barriers from pre-test to post-test ($N = 81$)

		Pre-test % (*n*)	**Post-test % (*n*)**	***P* 2-sided**	**Cramer's V**
	Yes, we face barriers	27.2 (22)	17.3 (14)	0.031	0.56
	Barrier type				
1	Long wait for services	17.3 (14)	3.7 (3)	0.004	0.25
2	No known treatment for disability	11.1 (9)	6.2 (5)	0.267	0.36
3	Services not available in my area	7.4 (6)	7.4 (6)	n/a	n/a
4	Transportation	6.2 (5)	1.2 (1)	n/a	n/a
5	Financial costs of services	11.1 (9)	6.2 (5)	0.065	0.44
6	Do not know where to go for services	14.8 (12)	9.9 (8)	0.003	0.53
7	Do not understand easily what professionals say	3.7 (3)	1.2 (1)	0.625	0.33
8	Poor treatment by professionals	7.4 (6)	6.2 (5)	0.508	0.47
9	Different beliefs about health care/disability services	4.9 (4)	2.5 (2)	n/a	n/a
10	Other types	8.6 (7)	8.6 (7)	0.774	0.45

The table displays positive responses only. Cramer's V effect size interpretation: small 0.10, medium 0.30 and large 0.50 effect. n/a, not applicable.

($P = 0.035$), speech therapy ($P = 0.032$), supported living or group homes ($P = 0.026$) and service coordination ($P = 0.013$). A marginal change was also noted in supported independent living ($P = 0.064$). The Cramer's V values associated with patterns of service use and need ranged from 0.26 (national caregiver organisations) to 0.57 (supported independent living), indicating that the effect sizes were medium to large.

Discussion

The purpose of this study was to examine if participation in the MI-OCEAN programme for ageing caregivers (50+) of adults with I/DD could reduce perceived barriers to accessing, using and needing formal service support. Overall, it was found that the programme had the potential to decrease barriers to accessing services and increase the use of desired services.

Barriers to accessing services

A significant reduction was found in the proportion of caregivers who faced barriers to accessing health and disability services. As a part of the peer mentoring process, FSNs taught caregivers to navigate systems through storytelling, shadowing and role playing until the caregiver learned the skill. As a result of learning strategies during the instructional support on self-advocacy, more caregivers reported knowing where to go for appropriate services and how to reduce wait time to receive services. This finding did not infer that the MI-OCEAN programme reduced wait times, but the strategies suggested during the intervention may have been useful in navigating the system to facilitate services in a timely manner. Our findings aligned with past research among caregivers of adults with autism that a systems navigation approach fostered a sense of caregiver empowerment and advocacy by increasing caregiver knowledge on accessing necessary services (Taylor *et al.* 2017).

Not surprisingly, the only barrier that did not decrease after completing the programme was the availability of services in the area. While participating in the project could have contributed to greater knowledge and advocacy skills to access locally available services, the barrier of lack of availability of services remains. Lack of availability of services was identified by almost a quarter of the families (predominantly under-resourced families in XX) who participated in a needs assessment study in the region (Samuel *et al.* 2012). Much work needs to be done to ensure equitable access to resources by geographical location.

Patterns of service use and need

The significantly greater use and reduced need for most services provided evidence that MI-OCEAN has the potential to help families navigate complex systems of care. Five (advocacy services, national and

Table 4 Change from pre-test to post-test on use and need for formal services

Formal supports	**Pre-test %**			**Post-test %**			**Change %**			**McNemar–Bowker**	**Cramer's V**
	Use	**Need**	**No**	**Use**	**Need**	**No**	**Use**	**Need**	**No**		
Health services											
1 Medical specialist	41.6	19.5	39.0	51.2	11.3	37.5	9.6	−8.2	−1.5	5.00	0.46
2 Chronic condition care	40.8	22.4	36.8	44.3	19.0	36.7	3.5	−3.4	−0.1	0.95	0.42
3 Social work	35.4	29.1	35.4	38.8	23.8	37.5	3.4	−5.3	2.1	1.89	0.38
4 Psychiatric services	30.4	26.6	43.0	39.2	16.5	44.3	8.8	−10.1	1.3	6.73	0.56
5 Counselling*	24.1	39.2	36.7	30.4	22.8	46.8	6.3	−16.4	10.1	12.40**	0.53
6 Behaviour support	17.3	42.0	40.7	28.2	34.6	37.2	10.9	−7.4	−3.5	4.57	0.54
7 Physical therapy*	10.7	22.7	66.7	6.3	21.3	72.5	−4.4	−1.4	5.8	8.60*	0.47
8 Occupational therapy	8.0	21.3	36.8	10.3	23.1	36.7	2.3	1.8	−0.1	1.53	0.36
9 Speech therapy*	6.8	29.7	63.5	13.9	17.7	68.4	7.1	−12	4.9	8.77*	0.53
Community living											
10 Community mental health	51.3	24.4	24.4	60.0	17.5	22.5	8.7	−6.9	−1.9	5.11	0.47
11 Service coordination*	40.5	46.8	12.7	54.3	27.2	18.5	13.8	−19.6	5.8	10.83*	0.38
12 Financial support	35.4	29.1	35.4	48.7	24.4	26.9	13.3	−4.7	−8.5	5.91	0.32
13 Disability support groups**	13.9	55.7	30.4	32.1	33.3	34.6	18.2	−22.4	4.2	12.69**	0.34
14 Adult day care	9.2	30.3	60.5	9.1	32.5	58.4	−0.1	2.2	−2.1	4.60	0.48
15 Supported employment	6.6	52.6	40.8	12.5	40.0	47.5	5.9	−12.6	6.7	3.94	0.45
Residential supports											
16 Group homes*	7.9	44.7	47.4	6.3	25.3	68.4	−1.6	−19.4	21	9.26*	0.52
17 Supported independent living	2.6	57.9	39.5	8.9	41.8	49.4	6.3	−16.1	9.9	7.25	0.57
18 Institution/large facility	2.6	7.9	89.5	0.0	5.1	94.9	−2.6	−2.8	5.40	n/a	–
Caregiver supports											
19 Respite care	27.8	53.2	19.0	32.9	41.8	25.3	5.1	−11.4	6.3	4.27	0.59
20 Advocacy services***	7.8	68.8	35.5	38.2	35.5	26.3	30.4	−33.3	−9.2	25.83***	0.29
21 State caregiver organisations*	7.8	63.6	28.6	16.5	43.0	40.5	8.7	−20.6	11.9	11.29*	0.29
22 National caregiver organisations*	6.8	54.1	39.2	17.9	35.9	46.2	11.1	−18.2	7	13.30**	0.26
23 Community caregiver groups**	2.6	68.8	28.6	18.4	47.4	34.2	15.8	−21.4	5.6	16.07**	0.32

*$P < 0.05$.

**$P < 0.01$.

***$P = 0.001$.

Use refers to 'We currently have this support', **Need** refers to 'We are in need of this support' and **No** refers to 'Not in need of this support'. Cramer's V effect size interpretation: small 0.10, medium 0.30 and large 0.50 effect. n/a, not applicable.

state caregiver organisations, disability support groups and community caregiver groups) of the 10 services that changed were related to advocacy and support. This finding strengthens past research that peer-mediated family support interventions can improve caregiver advocacy (Heller & Caldwell 2006).

There were also significant changes observed in the use and need for service coordination, counselling, physical and speech therapy from pre-test to post-test. After participating in the study, there was an increase in use of service coordination coupled with decrease in the need for service coordination, which is a formal support that assists caregivers and families in arranging care for their loved ones with I/DD. When service coordination is family-centred, research has shown that families exhibit decreased need for resources over time (Bruder & Dunst 2008; Childress *et al.* 2019). This finding was corroborated by the current study. As individuals with I/DD are living longer while their caregivers are declining in health, the importance of care coordination is crucial (Robinson *et al.* 2012). Further, the greater use of counselling services after participating in the study indicates that working with an FSN may have helped the caregiver not only to access counselling as a formal service but also provided them with a way to communicate their concerns to a peer, much like a counsellor.

The increase in service use occurred with a simultaneous decrease in perceived need for that service for most types of services. The only exceptions noted were decreased use of physical therapy, residential care in group homes, institutions and adult day care. The pattern observed in residential supports, although not statistically significant, was noteworthy because these trends indicated that MI-OCEAN services could foster supported independent living. As a point of reference, supported independent living arrangements can refer to various environments (e.g. own home or apartment and shared home arrangement with one to three other occupants) where some level of support is available if needed but is different from living in a large care facility or institution (a residence of seven or more people managed by an agency) or group home (six or fewer occupants with disabilities managed by an agency) due to the number of occupants and the level of care (Larson *et al.* 2021). By the end of the study, the use of supported independent living facilities increased, with fewer caregivers reporting the use of group homes and none using institutions. Together, these findings suggested that this peer-mediated systems navigation intervention can foster independent living of people with I/DD.

Study limitations

Limitations to be considered when interpreting the findings include the lack of a representative sample. Participants were primarily ‘younger’ older caregivers (with the majority between 60 and 69 years and their care recipients between 25 and 34 years old), White, educated, married and female caregivers with high family income. Caregivers disconnected from service systems, overwhelmed by caregiving responsibilities, and from lower socio-economic groups may have been inadvertently excluded from the study. Future recruitment efforts should target a more heterogeneous sample, including male caregivers along with greater racial and socio-economic status diversity.

The use of investigator-developed measures and the lack of a control group with random assignment of participants could affect the ability to determine if changes observed were the result of programme participation or other extraneous factors. The absence of fidelity data limited the internal validity of the study. A longitudinal analysis with data collected using standardised measurement tools over several follow-up periods could provide a richer understanding on how patterns of service use change as families progress through the stages of ageing and life transitions. Despite these limitations, the present study provides important findings regarding the understudied group of ageing family caregivers of adults with I/DD. Research should expand FSN programmes to different geographic areas and provide support to individuals with I/DD and their ageing caregivers.

Practice implications

Findings from this study can be beneficial for practitioners and researchers who desire to identify practical ways of helping ageing families who are caring for adults with I/DD. Peer mentors appear to be an effective way to support caregivers in understanding where to find services and how to reduce the wait times associated with some health care and disability services. Based on the results of this study, caregivers appeared to be able to increase their use of advocacy, support groups, support coordination and counselling, with a corresponding decrease in the need for these services. Social workers and other professionals should consider using peer mentors when caregivers experience changes in caregiving and struggle with navigating complex systems of care. Additional FSNs could be recruited from caregivers in the current study who were successful in meeting their goals and desire to help others who are challenged with the system.

Implications for further research

Research is needed on caregivers of adults with I/DD to fill the gap in the literature that focused primarily on young children and adolescents. Ongoing research should validate the benefits of using peer mentors to empower caregivers in dealing with the needs of the family that often includes multiple care recipients, including the individual with I/DD. Longitudinal research is needed to determine the long-term effects of using peer mentors to help ageing parents in finding resources as they and their care recipients age and their needs change. A qualitative study needs to be conducted with FSNs to examine their perceptions of how they can best support other caregivers of adults with I/DD.

Conclusions

Findings indicated that a peer-mediated family support project could empower ageing family caregivers by decreasing their perceptions of barriers to accessing health and disability services, increasing the use of support services and reducing service needs. Participants gained knowledge on obtaining desired services and reducing wait times associated with formal services. With the help of FSNs, caregivers were able to connect with support groups, obtain services and advocate for their family members including their adult children with I/DD.

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Conflict of interest

The authors have no sources of conflicts of interest to disclose.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All procedures performed in this study involving human participants were in accordance with the ethical standards of the Wayne State University's Institutional Review Board.

Data availability statement

Data from this study are available upon request.

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