Please cite the Published Version

Riches, Vivienne, O'Brien, Patricia, Manokara, Vimallan and Mueller, Arne (2023) A study of caregiver support services: perspectives of family caregivers of persons with intellectual disabilities in Singapore. Journal of Policy and Practice in Intellectual Disabilities, 20 (1). pp. 117-131. ISSN 1741-1122

DOI: https://doi.org/10.1111/jppi.12441

Publisher: Wiley

Version: Published Version

Additional Information: This is an open access article which appeared in Journal of Policy and Practice in Intellectual Disabilities, published by Wiley. It is part of the Special Issue "Families"

Received: 15 August 2021 | Accepted: 31 August 2022

DOI: 10.1111/jppi.12441

SPECIAL ISSUE ARTICLE

Journal of Policy and Practice in Intellectual Disabilities

A study of caregiver support services: Perspectives of family caregivers of persons with intellectual disabilities in Singapore

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Funding information
Movement for the Intellectually Disabled Singapore, Grant/Award Number: grant

Abstract

Most people with intellectual disabilities in Singapore live with family and are supported by family caregivers. Many caregivers lack the awareness, skills and resources needed for their caregiving role. A caregiver support service designed to build the capability of family caregivers serving children and adults with intellectual disabilities was evaluated after 2 years of operation to ascertain the level of caregiver coping and resilience, perceived impact of strategies for emotional support, and satisfaction with a range of support services and gaps in service. Family caregivers were surveyed regarding satisfaction with services received using the Client Satisfaction Questionnaire (CSQ-8) and feedback from activities and events. Their coping and resilience were measured with the Coping Competence Questionnaire (CCQ). Qualitative data from caregiver interviews and staff focus groups were analysed for key themes that were triangulated and converged with other findings. Satisfaction, better coping and resilience were associated with specific support services. Key themes emerged around several effective supports and areas of unmet needs across the lifespan. Limitations and areas for improvement were identified to meet a broader range of caregivers. Targeted family support services can enhance the well-being of caregivers supporting people with intellectual disabilities (ID) across the lifespan. The results inform policymakers and support agencies that support of the family, not just the person with ID, is an important factor and needs to be incorporated at the heart of the design and development of any inclusive community living in Singapore.

KEYWORDS

family caregivers, intellectual disability, practice, resilience, satisfaction, support services

INTRODUCTION

Interest in family caregiver support has increased as more people with intellectual disabilities (ID) live in the community with their families in preference to transitioning into residential group home settings. There is little research on how best to support family caregivers but there is growing evidence of both positive and negative impacts of caring for a person with ID. These influencers can affect family quality of life, and caregiver coping and

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resilience (Brown et al., 2010; Ho et al., 2013; Isaacs et al., 2007; Llewellyn et al., 2003; Roth & Brown, 2017; Werner et al., 2009).

Economically, caregiving is typically measured in terms of savings to governments and welfare systems from the use of natural supports (NAC and AARP Public Policy Institute, 2015). This is because most family caregiving involves unpaid, natural support. Other caregiver measures commonly reported are the type of care provided, time spent caring for others on a typical day, week, month, or year, personal demands on caregivers, and the cost of caregiving to the caregiver, the individuals being cared for, their families, and society (Llewellyn et al., 2003; NAC and AARP Public Policy Institute, 2015). Clearly, caregiving can have negative financial impacts on families. The cost of lost wages for caregivers who are unable to work and loss of employee hours and days of work when coping with illness or crises can be significant for family finances (Leonard et al., 2016; NAC and AARP Public Policy Institute, 2015).

High levels of stress and burnout and the burden of care associated with time taken in caregiving, as well as difficulties with poor levels of family support have been reported (Beresford, 1996; Chou et al., 2009; Hatton et al., 1998), along with challenging behaviour (Hastings, 2002), and problems with services (NCSS, 2016). These can contribute to caregiver depression, helplessness, and poorer emotional well-being (Hayden & Goldman, 1996; Hayden & Heller, 1997; Llewellyn et al., 2003; Mori et al., 2018; Schroder & Ollis, 2013; Seltzer & Krauss, 1989). Chronic stress and negative health impacts due to the extended duration of caregiving have also been found among older caregivers (Pearlin et al., 1981). In contrast, some family caregivers assert that their caregiving role provides meaning to their lives and personal fulfilment. Examples include opportunities for development, increasing appreciation of diversity, and strengthening family relationships (Llewellyn et al., 2003; Werner et al., 2009).

There is a paucity of information on how best to support caregivers of persons with ID apart from respite and out-of-home care services. Neves et al. (2017) found caregivers of dependent individuals required knowledge and skills, resources, and strategies to enhance coping and well-being. They recommended intervention projects be initiated and caregivers receive effective support from health professionals. The outcomes of such interventions need to be shared globally, particularly in the South Asia region where doing research is fragmented, often arising from a lack of funding (Kalyanwala et al., 2019) with less focus on outcomes being published within peer-reviewed journals. This study was instigated by a large not-for-profit disability organisation in Singapore with the aim of closing such a gap.

Singapore is a multiracial and multicultural sovereign state with a population of 5.70 million. Ethnic groups categorise as Chinese, Malay, Indian and other. Malay is the National language, but English is the main language spoken. Basu (2013) estimated that 210 000 people in Singapore aged 18–69 provide regular care to family and friends and that demographic trends over the next several decades are expected to reduce the supply of informal caregivers and increase the demand onto a smaller number of caregivers per elderly person with a disability. This is a significant concern as the National Council of Social Service (NCSS) estimated the number of people with disabilities 18 years and above (excluding mental health conditions only) at 77 200 with 30.4% of these having more than one disability, and 16.2% severe disability. The study reported that caregiver participants in Singapore were in constant survival mode. Many lacked the skills and resources needed for their caregiving role. They also lacked awareness and knowledge of how social services worked, and of how to care for themselves. Moreover, the quality and level of assistance received were dependent on the knowledge and experience of their providers (NCSS, 2016). A greater continuum of caregiver services of support, including respite and provision of adequate training and self-care to prevent burnout, was recommended (NCSS, 2017).

The Singapore government views the family as the most critical part of the social fabric of the country such that the mission of the Ministry for Social and Family Development (MSF) is to nurture resilient individuals, strong families, and a caring society (Ministry for Social and Family Development, 2011). Hence, caregiver capacity building is given considerable emphasis. The Government is also committed to realising its obligations under the United Nations Convention on the Rights of Persons with Disabilities. Singapore signed the UNCRPD on 30 November 2012, ratified the convention on 18 July 2013 and submitted its initial report in 2016 (Singapore Committee on the Rights of Persons with Disabilities, 2016). Consequently, the Ministry of Social and Family Development's Enabling Masterplan is a roadmap for Singapore to build a more inclusive society where persons with disabilities are empowered and enabled to realise their true potential. The 3rd *Enabling Master Plan* 2017–2021 (MSF, 2016) recognised that caregivers play a critical role in caring for persons with disabilities and highlighted three key concerns: preparing for the future, performing the role of a caregiver well and the need for self-care and respite. The *4th Enabling Master Plan* 2022–2032 (MSF, 2022) also carries this focus on caregiver wellness and resilience.

In this context, a large Singaporean not-for-profit organisation serving people with ID initiated a formal Caregivers' Support Service (CSS) in 2015. The aspirational objectives of the CSS were subsequently aligned to Singapore's 3rd *Enabling Master Plan* 2017–2021 (MSF, 2016): (1) to build the capability of caregivers to enhance their caregiving role, (2) to provide resources necessary to empower and enable caregivers to participate fully in the economic, social, and cultural life of the community and (3) to support family social–emotional needs (Chan, 2017). The organisation runs four special schools, three post-school employment programs, six post-school day programs and one residential service catering to people with ID across the lifespan. The needs of caregivers across this array of services, therefore, were potentially diverse.

After two years of operation, an independent evaluation of the CSS was commissioned as part of a larger study that also explored family quality of life. The specific aims of this part of the study were to ascertain:

- The level of coping and resilience of caregivers participating in CSS activities.
- The perceived impact of strategies intended to provide emotional support such as family and social connections and networking sessions.
- Caregiver satisfaction with CSS knowledge and skill-building workshops and events designed to support families in their caregiving role and any gaps in support.
- Any differences in caregiver needs and responses according to demographics of individuals with ID being cared for.

METHODS

Procedure

All caregivers registered in the CSS program who had attended activities between 2016 and 2018 were invited to participate in the study survey through the organisation's email database and newsletters using ethics-approved forms and procedures. Ethical approval was obtained from the University of Sydney Human Research Ethics Committee. Caregivers could choose to complete the survey via mail, online, or by face-to-face interview with a trained social worker unknown to the caregiver at one of 14 CSS locations. Verbal translation support was offered to all participating caregivers.

Invitations to participate in an in-depth face-to-face interview were sent to a randomised sample of 60 caregivers who had completed the survey. A convenience sample of the first 36 respondents were interviewed. This number reflected pragmatic considerations of the number of interviews that could be facilitated by professionally trained social workers in the evaluation timeframe. The expectation was also that data saturation would be reached with this number, with in-depth interviews identifying all key themes and issues with this number (Fusch & Ness, 2015). In-depth interviews were held at a CSS location closest to where the caregiver lived. Translation services using staff were offered. Interviews were recorded with permission, de-identified and transcribed for analysis.

Focus group invitations were sent via flyers and newsletters to CSS staff at each location. At least one staff volunteered to represent each location. Three identical half-day focus groups were conducted over a 2-day period to accommodate busy staff timetables. Additionally, two key managers were interviewed individually. Summary evaluation results from 2016 to 2018 workshops and events had been collated by CSS staff and these were forwarded to the evaluation team for examination.

Results from all quantitative and qualitative data sources from the survey questionnaires, in-depth interviews, staff focus groups and interviews were then examined and triangulated for key themes. The thematic outcomes arose from considering where the findings from the sets of data converged and/or contradicted each other, with the latter offering complementary information to the interpretation of the data.

Participants

A total of 328 caregivers were recruited who chose to complete the survey in English online or face-to-face with an interpreter if desired. Most caregivers were parents (77.7%), followed by siblings (18.9%), "aunties"[1] (2.1%) and grandparents (1.2%). This response rate represented 75% of caregivers who had participated in one or more support services over the previous 2 years. Caregivers were supporting 335 family members; all of them had ID. Of these 189 were male (56%) and 140 (42%) were female. Ages ranged from 7 to 64 years, with the average age being 26 years (SD = 12.2). Many individuals receiving care had additional disabilities, health, and other conditions. These included speech and language disorders (49%), behaviours of concern such as hurting self, others or objects, or socially excluding behaviours such as screaming and repetitive behaviours that stopped them from doing things other people do (39%), mood and anxiety (36%), genetic syndromes (Down, Prader Willi, Fragile X, Williams, Turners etc 31.7%), health conditions such as heart and gastro-intestinal/digestive conditions (18%), Autism Spectrum Disorder (15.5%), sensory disabilities (visual 7%, hearing 3.7%) and epilepsy (9.5%). Most caregivers judged they were providing medium to high levels of support (Table 1 for demographic information).

Caregiving was provided at home, in two-parent families (73%), in one-parent families (22%) or in other family settings (with siblings 18.8%, aunties 2.2% and grandparents 1.2%). Four individuals (1.2%) lived in a residential facility with intermittent support from a sibling.

A sample of 36 of the 328 caregivers surveyed were also interviewed face to face. Half of these were fathers (50%), followed by mothers (36%) and siblings (14%). Interviewees ranged in age from 31 to over 70 years. A third were aged 41–50 years and over 61% were 50 years plus. They came from five different ethnic backgrounds: Chinese (61.1%), Malay (19.4%), Indian (13.9%) and Filipino and Sri Lankan (2.8% each). Religious backgrounds nominated were Buddhist (25%), Muslim (25%), Christian (25%), Hindu (5.6%), Taoists (2.8%), "free thinkers" (8.3%) and non-religious (8.3%). Both survey and interviewee samples represented a wide cross-section of CSS caregivers according to gender, age, and cultural background.

A total of 27 staff associated with the CSS also participated. Three focus groups were attended by 25 staff comprising managers, assistant managers, heads of centres, supervisors, acting supervisors, staff coordinators, social workers, speech therapists, case workers, trainers and CSS sub-committee members. Staff roles involved organising and carrying out caregiver networking events, activities, and workshops and attending CSS meetings. At least one staff member represented each of the 14 CSS location sites. Two additional senior CSS managers were interviewed independently. Summary data for staff participants are reported in Table 1.

Measures

Both quantitative and qualitative data were collected to provide a rich understanding of the key questions (Creswell & Clark, 2017). The survey involved two instruments that had not previously been used in the Asian context but in the design phase, had been checked by a steering committee involving Singaporean psychologists and social workers and deemed suitable and culturally appropriate for use in the evaluation. The *Coping Competence Questionnaire* (CCQ) (Schroder & Ollis, 2013), a 12-item scale that originated in Germany, was translated into English, and validated on US populations. It is designed to assess resilience against helplessness and depression. Low scores are indicative of a propensity towards the development of helplessness and depression while high scores indicate resilience against stress and helplessness and a general ability to cope well with negative life events, challenges and failures. Items are scored using a 6-point Likert scale from 1 (*very uncharacteristic, unlike me*) to 6 (*very characteristic, like me*). Scores are reversed and summed to obtain a Total CCQ as an indicator of "coping competence". Total scores can range from 12 to 72 with higher scores representing greater ability to navigate well when challenges arise, while low scores indicate vulnerability towards helplessness and depression. The CCQ has excellent internal reliability with an overall coefficient alpha of 0.93. The test–retest reliability after 1 month was high ($r = 0.86$). Factor analysis confirmed a unidimensional scale with good convergent and discriminant validity (Schroder, 2005; Schroder & Ollis, 2013).

The *Client Satisfaction Questionnaire (CSQ-8)* (Larsen et al., 1979) is an eight-item instrument that measures client satisfaction with services received. It has been used across a wide range of mental health and human services settings. It uses a 4-point Likert rating from 1 (*poor, very dissatisfied*) to 4 (*excellent, very satisfied*). Total scores can range from 8 to 32, with higher scores indicating greater satisfaction. Several studies report high internal consistency with coefficient alphas ranging from 0.87 to 0.93 and good construct validity against other service and therapy outcome measures (Attkisson & Greenfield, 2004; Attkisson & Zwick, 1982; De Wilde & Hendriks, 2005).

Demographic questions collected the caregiver's relationship and caring responsibilities, the dependent's age, gender, disabilities, behaviour of concern and communication difficulties and level of support required.

The in-depth interview schedule comprised open-ended questions about goals for attendance, type and frequency of CSS services attended and received, satisfaction with services, and opinions on the impact of services, challenges and ideas for enhancing or improving the service.

Focus group and manager interview questions were based on the person-centred thinking and planning tools by Helen Sanderson "*Important to and Important for*" and "*Four + One Questions*": *What has been tried? Learnt? Pleased about? Concerned about? + What next?* (Stirk & Sanderson, 2012). Focus group participant minimum data for age band, length of service with the organisation, role with the CSS, and CSS location were collected anonymously.

Summary workshop and events evaluation data that were reviewed used different formats. Eight Microsoft excel spreadsheets listed activity title, trainer or vendor, date, organising centre, number of attendees, costs and satisfaction levels using a 4-point Likert scale from 1 (*poor*) to 4 (*very satisfied*). Some included participant comments. Six Microsoft Word documents provided numbers and satisfaction ratings with qualitative comments and photographs.

Data analysis

Quantitative survey data from the CCQ and CSQ-8 scales were collected and managed using REDCap, a secure, web-

TABLE 1 Summary data of study participants

Sample	Participant details	*N*	%
Family caregivers	Mothers	166	50.6
	Fathers	81	24.7
	Parent[a]	4	1.2
	Siblings	61	18.6
	Aunties	7	2.1
	Grandparent	4	1.2
	Unknown	5	1.5
	Total	328	100.0
Dependent with ID ($N = 335$)			
Gender	Male	189	56.4
	Female	140	41.8
	Gender unknown	6	1.8
	Total	335	100.0
Age range	0–16 years	79	23.6
	17–25 years	95	28.4
	26–35 years	73	21.7
	36–45 years	56	16.7
	46–55 years	17	5.1
	56 years+	6	1.8
	Unknown	9	2.7
	Total	335	100.0
Primary disability	Intellectual	335	100.0
Number of additional disabilities and health conditions	1	102	32.3
	2	94	29.7
	3 or more	78	26.9
Caregiver interviewees $N = 36$			
Relationship	Fathers	18	50.0
	Mothers	13	36.1
	Siblings	5	13.9
	Total	36	100.0
Age range	31–40 years	2	5.6
	41–50 years	12	33.3
	51–60 years	14	38.9
	61–70 years	7	19.4
	71 years +	1	2.8
	Total	36	100.0
Staff participants ($N = 27$)			
Age range	21–50 years	17	63.0
	51–65 years	10	37.0
	Total	27	100.0

(Continues)

TABLE 1 (Continued)

Sample	Participant details	N	%
Length of time with Organisation	6–12 months	6	22.2
	1–2 years	3	11.1
	3–5 years	13	48.1
	5–10 years	3	11.1
	Unknown	2	7.4
	Total	27	100.0

[a]Mother or father not specified.

based application (Harris et al., 2019). Data were then transferred to SPSS Version 22 (IBM Corp, 2013) for statistical computations. Missing data especially in the CSQ-8 meant results for individual questionnaire items were analysed according to the number of respondents completing each item. For CSQ-8 and CCQ totals, the formula for a maximum of two missing variables was used to calculate the mean for missing data and this was inserted in place of the missing value. This procedure did not change the mean or standard deviation for the sample. Total scores were not calculated for cases with more than two missing items.

Descriptive statistics were computed to examine levels of coping and resilience and satisfaction with services among caregivers. Additionally, the effects of independent variables for a person with disabilities being cared for, comprising gender, age, level of disability support needed, level of communication, presence/absence of behaviour of concern, and level of caregiver responsibility for a person with ID were examined against caregiver client satisfaction (CSQ-8) and coping competence (CSQ) using one-way ANOVA with post hoc comparisons.

Qualitative data analysis software MAXQDA 11.2.5 was used for all qualitative questions from interviews and focus groups. Questions were first analysed using the conventional content analysis approach where coding categories are derived directly from the text data (Hsieh & Shannon, 2005). Summarising codes were then applied to quotations of similar content, except for two questions for frequency of supports and overall satisfaction that were transformed into a variable to allow a more descriptive and quantitative analysing approach. Following the initial coding, a second round of axial coding was processed per answer to find more general codes and thematic areas that helped to better interpret and structure the content of the interviews and the answers given. Thus, a coding system with main and sub-codes per question emerged that was agreed on by two researchers. The coding system was then used to determine, emphasise, and quantify thematic areas of interest among researchers. Themes were then named and later triangulated against the other data sources for convergence or otherwise as described above. The research team then agreed that the findings needed to reflect an integrative and comparative relationship between measures, outcomes, and participant voice which in the study came from survey, interview, and focus group responses. This led to cross-checking and reflection of themes between researchers.

RESULTS

The CSS was initiated to support caregivers of clients with ID across the organisation's child and adult services. It operates as a hub and spoke model that is overseen by a subcommittee constituted by the organisation's Board of Directors. The hub funds and monitors caregiver support activities and initiatives and consists of a consultant supported by two allied health professionals and a clerical assistant. The spokes are 14 centre locations across Singapore. The spokes have the autonomy to identify and tailor support services to meet local caregiver needs, using organisation staff and external consultants.

From April 2016 to March 2018, the CSS provided information to its caregivers through an occasional newsletter and conducted 66 activities attended by 1336 family caregivers. Many activities were run by the organisation's allied health professionals and involved caregiver social/bonding activities, family day events, respite care days and camps during vacation time, sibling outreaches and camps, leisure and recreation activities, and celebration and appreciation events. Additionally, 20 knowledge and skills training workshops attended by 268 caregivers were presented by organisational staff or paid external consultants. These addressed practical areas such as managing behaviour of concern, effective rule setting, functional daily living skills, communication, future care-planning and financial issues.

Key themes

Six key themes emerged from analyses and triangulation of all data sources concerning the study aims of level of coping and resilience of caregivers, the impact of the CSS services and supports and differences in need according to demographics of individuals with ID being cared for. Data from the measures, caregiver interviews and staff focus groups were closely aligned. Evidence of themes across each of the data sources is outlined in Table 2 and their integration is further explained below.

Coping and resilience

Survey data, caregiver Interviews and staff focus groups all identified that CSS-run bonding, family and social networking sessions and social sharing opportunities had a positive and beneficial effect on caregiver emotional well-being, reducing stress, isolation, and loneliness.

Total scores for *The Coping Competence Questionnaire—Dealing with Stressful Situations (CCQ)* spanned the entire range of possible scores (12–72), indicating coping competence varied widely among the 290 participants who completed all items. The mean score was positive at 48.39 (SD = 12.8). The distribution was negatively skewed, with three quarters registering good through excellent coping and resilience. However, 20 carers (7%) had very low scores from 12 to 24, while another 33 (18%) had low scores between 25 and 36 (Table 3 for details).

Age of the person with disabilities being cared for (and by implication age of caregivers) was significant $F(5,301) = 3.77$, $p < 0.01$. Significantly lower coping scores were found among caregivers of older adults (36–45 years, $M = 44.2$) and children (0–16 years, $M = 45.6$) than scores for caregivers of young adults aged between 17 and 25 ($M = 50.9$) and 26–35 years ($M = 51.9$). No significant relationships were found between caregiver coping scores and family members' level of disability support needed, level of communication support required, presence/absence of behaviour of concern, or level of caregiver responsibility for person with ID (Table 5 for details).

Most caregivers interviewed reported that services had helped to relieve stress levels and supported them to better understand both their family member's strengths and other caregivers' perspectives. Talks on long-term care plans, legal talks, courses on financial issues, information on a Special Needs Trust Company saving scheme, skills to work with children, behaviour management, cooking classes, and accommodation issues were all positively commented upon. One father commented, "I am rather impressed with the talks and events for caregivers that (the organisation) have introduced in the recent years. Implementation of check-ups and other services. Talks on leaving a financial means to take care of person with disability etc. have helped a lot".

Many caregivers of older adults with ID expressed concern about the future and future planning, especially as parents aged. Caregivers of children below 16 years and young adults appeared more concerned about gaining knowledge, skills and competencies needed in their caring roles. They were often heavily involved in assisting with basic activities of daily living, behaviour of concern and risk management. Some expressed a need for additional respite and in-home respite. One mother shared her hopes for the organisation "to provide more respite care services, specifically in relieving caregivers for short hours when they need to run errands or attend to important matters in which there are no alternative caregivers."

Where stress levels remained high, interviewees referred to specific stressors. These were behaviours of concern; embarrassment about behaviour in public; struggles caring for additional dependent family members such as ageing parents and parents with health challenges; juggling multiple roles when working full time; helping illiterate parents with bills and other administrative matters; caring for siblings; and men managing female hygiene issues.

Bonding, networking and social connections

Bonding and networking opportunities provided were regarded as extremely helpful as they enabled caregivers to gain mutual support from one another. Indeed, bonding and networking events were the primary goal and motivation for attendance at CSS programs for many of those interviewed (67%). Another 14% nominated learning skills and interacting with other families as their primary goals for attendance. Several caregivers acknowledged they had other relationships such as faith-based groups, who provided this support. While support gained from CSS staff and their services were appreciated, caregivers shared how mutual benefits were gained from talking with and supporting each other. They reported bonding, networking, and sharing opportunities had helped relieve stress, facilitated mutual social and emotional support, and assisted caregivers to feel understood and no longer isolated. This was especially noted among fathers, one of whom stated: "The family bonding activities do provide us a platform to contact with other caregivers – share our parent-child experiences with each other." Another father responded, "Through the network sessions, such as group work, it feels good that you are not alone. I have friends who can only pity me. But with fellow caregivers, we really feel we know our problems together."

Staff focus group data corroborated caregiver statements about the importance and value of bonding and

TABLE 2 Key themes identified across data sources

Theme	CCQ $N = 316$	CSQ-8 $N = 291–216$	Carer interviews $N = 36$	Events and workshop evaluations	Staff ($N = 27$)	Comments
Coping and resilience, stress	✓		✓	✓	✓	Positive impact of services. Additional and ongoing stressors identified
Bonding, networking and social connections	✓	✓	✓	✓	✓	Primary goal for attendance for many caregivers. Significant positive benefits for caregivers, families and person with ID
Knowledge and skills development		✓	✓	✓	✓	Most valued by caregivers of children and young adults e.g. behaviours of concern, communication, activities daily living
Future planning and financial concerns among older caregivers	✓	✓	✓	✓	✓	Concerns for future when caregiver unable to continue caring
Additional unmet needs especially respite	✓	✓	✓	✓	✓	Respite, supports for behaviour of concern, financial needs, development across the lifespan, person-centredness
Need to engage additional carers through greater flexibility in service provision			✓		✓	Significant number of caregivers not engaged; need for greater flexibility for events outside normal working hours, times selected and locations, translations services to be provided

Abbreviations: CSQ-8, Client Satisfaction Questionnaire; ID, intellectual disabilities.

networking provisions. Caregiver feedback specifically highlighted the importance of caregivers' personal, social, and emotional support needs and the value of staff facilitating these supports through CSS initiatives. Opportunities for giving and receiving personal and emotional support along with developing social connections, gaining specific informal and formal supports, recreation and leisure, family bonding sessions, respite, and workshops were all identified as top priorities for CSS attendance. Staff confirmed they had observed caregivers attend events regularly and form close relationships that provided mutual support that enabled them to share experiences and knowledge that extended well beyond the CSS program initiatives. Managers interviewed added that feedback had resulted in CSS activities being broadened to include extended family members and sibling camps.

Knowledge and skills development

The provision of knowledge, information, and resources to enable caregivers to better cope with and manage their caring roles was another key theme that emerged from the data. Workshop topics (listed previously) were provided in response to caregiver needs and were positively received. Several interviewees identified they also required knowledge and skills to understand the developmental needs of their child across life stages and skills and techniques to better understand the person-centred approach for their child and family. Knowledge and skills development workshops were particularly valued by caregivers of children and young adults. One mother explained, “I feel that I have still a lot of skills I do not know about … how to teach my daughter and would like to attend more workshops in this aspect. Example: How to teach her to count money? How to be more street smart and protect herself from moral dangers?”

Future planning and financial concerns among older caregivers

There was obvious concern for the future among ageing caregivers. Various workshops had addressed future planning and finances, but additional resources and support were requested especially as parents age or pass away. For example, a sibling (translated by staff) noted “the most important area … that of the client's long-term care

TABLE 3 Coping competence (CCQ) results ($N = 316$)

Item	Mean	SD	Score[a] range
1. I become easily discouraged by failures	4.0	1.3	1–6
2. When my performance does not satisfy, I start to question my abilities	3.7	1.5	1–6
3. I often feel unable to deal with conditions	4.2	1.3	1–6
4. Failures can shake my self-confidence for a long time	4.0	1.5	1–6
5. When I am confronted with unusual demands, I feel helpless	3.9	1.4	1–6
6. When I do not immediately succeed in a project, I quickly loose hope for a good outcome	4.1	1.4	1–6
7. When I cannot solve a task, I blame my lack of abilities	4.1	1.4	1–6
8. When I fail at something, I tend to give up	4.0	1.4	1–6
9. When my work is criticised, I feel depressed	3.7	1.6	1–6
10. I often feel overpowered by obstacles and troubles	3.9	1.7	1–6
11. I lose faith in myself when I make mistakes	4.3	1.3	1–6
12. If I do not instantly succeed in a matter, I am at a loss	4.4	1.2	1–6
CCQ total	48.4	12.8	12–72
Coping competence total score	***N***	**Percent**	**Cum %**
12–24	20	6.9	6.9
25–36	33	11.1	18.3
37–48	88	30.4	48.6
49–60	103	35.5	84.1
61–72	46	15.8	100.0

Abbreviation: CCQ, Coping Competence Questionnaire.
[a] Items scores reversed so higher score = greater coping competence.

upon parents' eventual death. As parents continue to advance in age, they assert this to be their main priority of concern at this current stage".

Additional unmet needs

Although many caregivers were happy with the services received, satisfaction data identified over 30% of caregivers required additional services and support. Interview and staff focus group responses confirmed more assistance and further services or activities were required to address respite, specific communication and behavioural concerns, information in long-term care planning, and medical and financial services and supports. Although appreciation was expressed regarding some financial assistance provided, several families reported they faced additional disability-related costs for therapies, travel etc., which placed them under considerable financial stress.

Respite care services were identified as a particularly critical need. One couple was thankful for any support but needed much more respite than was available "We (as the mother and father) need to have respite, for a week or two, from having to take care of our son. We are more unfortunate than others in that our son has severe amnesia, and he throws tantrums most of the time, including upsetting chairs and throwing things. In this … his half-day at (organisation's) workshop is a great help". Other comments identified a need for short-term respite to relieve caregivers for several hours to run errands or attend to important matters including a parent who responded, "Good if there are short respite services in the home for caregivers to purchase. Services could be for a few hours or half a day within the home so that parents can have some time off."

One mother was highly critical of the lack of services received by her school-aged child, but it was unclear if this mother had received any support from the CSS. "Intervention to kid not rendered … No proper feedback on kid's condition and area for improvement … School bus do not goes to her after school care …. No-one in-house after school care, need to hire private driver."

Flexible service delivery

Both survey and interview data highlighted difficulties for those speaking languages other than English, such as older parents who spoke only Mandarin or Tamil. Data from interviews and the CSQ-8 revealed that oral and written translation services were requested not only to participate meaningfully in research but for all general written information and when attending CSS events. One sibling requested "Please consider the need of providing bilingual material for future correspondences. There are still a large number of caregivers like my old parents who cannot read English and speaks only dialects". One parent commented that, "Regular home visitation by social workers to collate the voices from the ground would be helpful to realistically improve services rather than surveys."

Interview and focus group data identified various family caregivers had full-time working commitments, with household duties and caring responsibilities that often involved high and complex disability needs. They faced logistical difficulties preventing attendance at workshops and activities due to work and caring commitments, especially as sessions typically were run during regular working hours. For example, a parent commented, "Besides, it would be better if the workshops are conducted at night and on weekends as most caregivers are not free on weekdays."

Caregiver satisfaction with support services

A specific aim of the study was to ascertain caregiver satisfaction with CSS supports. Satisfaction Questionnaire (CSQ-8) total scores were available for 291 caregivers when the missing data formula for one or two missing questions was applied. Several caregivers stated they did not complete this questionnaire at all because they had not participated in CSS services due to lack of time, while some respondents did not complete three or four questions they did not understand or did not know how to answer. The satisfaction of responding caregivers was generally positive. The overall mean was 23.41 (SD = 3.64), individual item means ranged from 2.75 to 3.15 and 91% rated the overall satisfaction with services received item as good or excellent (Table 4). Most caregivers (83%) responded the kind of services provided were good to excellent and that services had helped them to deal more effectively with their problems (88%). The highest rated CSQ-8 items indicated respondents would recommend the CSS program to a friend in need of similar help ($M = 3.23$, SD = 0.59) and that they would attend additional programs if further help was needed ($M = 3.15$, SD = 0.61). However, poor or fair ratings were evident for over a third of caregivers (37%) regarding the extent to which their needs had been met ($M = 2.71$, SD = 0.65). Many required additional help (34%, $M = 2.75$), and 29% indicated they were not satisfied with the quality of the service ($M = 2.81$, SD = 0.62). These were also the questions that several caregivers failed to answer.

Analysis of variance with post hoc comparisons revealed a significant relationship between caregiver satisfaction with services and level of communication of the person being cared for $F(4,309) = 2.52$, $p < 0.05$. Caregivers whose dependents had some meaningful communication ($M = 23.9$, SD = 3.48) or no meaningful communication at all ($M = 23.43$, SD = 4.06) indicated significantly greater satisfaction than caregivers supporting individuals with limited communication for basic needs and wants ($M = 22.75$, SD = 3.76). No significant relationship was found between caregiver satisfaction and age of the person with disabilities being cared for, level of disability support needed, presence of behaviour of concern or level of caregiver responsibility for their family member with ID (Table 5).

Available summary evaluation data for 38 of 66 (58%) CSS social and emotional support activities and events indicated good (41%) to high satisfaction (68%) with activities and no dissatisfaction. Summary evaluations from 17 of 20 training workshops attended by 268 caregivers yielded similar results and indicated many caregivers attended multiple events.

Interview data supported these responses, with 81% of interviewees very or mostly satisfied with CSS events and services. A high level of appreciation was expressed acknowledging the invaluable support and assistance provided by specific CSS staff running activities, courses and workshops. Several parents thanked individual staff members by name, CSS staff in general and/or the organisation; for example, one mother commented, "Thank you for being there when needed though it's not easy. Lots of appreciation to each and every member of the … family" and "I am truly appreciative of the people in the organisation that cross my path and thankful for all their efforts and time … Their commitment and determination has to be applauded."

TABLE 4 CSQ-8 descriptive statistics

CSQ-8 item	*N*[a]	Mean	SD	1 poor %	2 fair %	3 good %	4 excellent %
1. Quality of service received	316	2.81	0.62	0.6	28.8	59.5	11.1
2. Kind of service you wanted	313	2.96	0.55	0.3	16.0	70.3	13.4
3. Extent program has met your needs	310	2.71	0.65	1.3	36.1	52.9	9.7
4. Recommend our program to a friend in need of similar help	312	3.23	0.59	0.0	8.7	59.6	31.7
5. Satisfaction with amount of help received	313	2.75	0.65	0.3	33.9	56.2	9.6
6. Services received helped deal more effectively with your problems	312	2.99	0.50	0.3	12.2	75.6	11.9
7. Overall satisfaction with service received	313	3.00	0.61	0.6	8.9	66.2	24.5
8. If to seek help again, would come back to our program	314	3.15	0.61	0.3	8.9	66.2	24.5
CSQ-8 total score	291	23.41	3.64	Range 14–32			

Abbreviations: CSQ-8, Client Satisfaction Questionnaire.

[a] Number of valid responses varied across items.

TABLE 5 ANOVA table of independent variables with caregiver level of satisfaction (CSQ-8) and coping competence (CCQ) totals

	Coping competence CCQ			Client satisfaction CSQ-8		
Variable	***F* ratio**	**df**	***p* value**	***F* ratio**	**df**	***p* value**
Age of person with disability	3.77	5306	0.01**	0.28	5276	0.93
Level of disability support needed	1.18	4307	0.32	0.22	4278	0.93
Level of communication	0.44	4314	0.08	2.52	4284	*0.04
Presence/absence of behaviour of concern	0.26	1315	0.61	0.37	1289	0.85
Level of caregiver responsibility for person with ID	1.37	4310	0.25	0.49	4282	0.74

Note: $^*p < 0.05$; $^{**}p < 0.01$.

Abbreviations: CCQ, Coping Competence Questionnaire; CSQ-8, Client Satisfaction Questionnaire.

However, 11% were neutral or mildly dissatisfied due to additional unmet support needs.

Staff focus group data and interviews with two managers supported the hub and spoke structure of the CSS. Reports were that the hub staff sourced and provided important external funding for activities, co-ordinated and monitored communication and activities and were responsible for program improvement. However, the ability to plan and deliver specific professional development regarding best practices in supporting caregivers was identified as a current gap. The autonomy of the spokes was valued by staff who responded that location-based staff assisted in identifying and delivering supports tailored to known local caregiver needs.

DISCUSSION

The Caregivers Support Service (CSS) was established in recognition of the need to better support family caregivers in Singapore across the lifespan. Results indicate many of the CSS initiatives played an important role that contributed to better coping and resilience, reduced stress and loneliness and developed stronger family relationships for many families. What is noteworthy is that these options were mostly provided within the organisation using existing allied health staffing and resources, with some supports outsourced to specialist consultants at an hourly fee.

The very high value placed on opportunities for improved family bonding and social networking is consistent with other studies that have found family relationships are extremely important (Brown, 2013; Correia et al., 2017; Werner et al., 2009). Challenges with caregiving for a child with a disability can result in smaller natural support networks and more reliance on health care professionals. It is not surprising then to find provisions for caregivers to develop social networks with other caregivers were perceived very positively. Indeed, both informal and formal mutual support for caregivers has been associated with better physical health (Cipolletta et al., 2018), mental health (Chien, 2008) and dementia care (Wang & Chien, 2011), especially in the Asian context. Caregivers in this study reported opportunities to contribute meaningfully to one another by giving and receiving emotional, social, and practical support, listening, sharing and problem-solving together in culturally sensitive ways were especially valued. This resulted in increased feelings of competence and self-esteem. The mean coping and resilience score of these caregivers ($M = 48.4$) was positive and comparable to a sample of students in the USA ($M = 49.78$, SD = 11.63) reported by Schroder and Ollis (2013) and higher than means found among samples of chronic disease patients (range $M = 35.0$, SD = 7.4 to $M = 36.8$, SD = 6.0) reported by Schroder (2005).

Interestingly, Quittner et al. (1990) found professional support was effective in acute stress conditions but may not be as effective for long-term and chronic stress. The study found that over time caregivers felt judged, increasing feelings of incompetence, and resulting in perceptions that supporters were critical and unhelpful. In contrast, peer support that was reciprocal in nature was positively viewed by long-term caregivers. These results along with our findings of the value of peer support suggest the relationship between resilience and family bonding and social networking is a promising area warranting further exploration among caregivers of persons with ID, especially across the lifespan.

It is concerning that some caregivers obtained very low CCQ scores. According to Schroder and Ollis (2013) lower sum scores indicate a greater propensity towards the development of depression and feelings of helplessness in the face of hassles and more frequent use of dysfunctional coping strategies. Such results indicate further efforts are required to ensure early identification and better-targeted support for vulnerable caregivers, across the life course. Knowledge and skill training workshops were greatly valued by caregivers of children. Other successful but more intensive programs designed to increase caregiver well-being, often provided in the early years, could also be trialled by the CSS. These include cognitive behaviour group interventions (Hastings & Beck, 2004), support groups for grandparents (McCallion et al., 2004) and early intervention supports promoting family empowerment and well-being (Dempsey & Dunst, 2004). Moreover, it appears a key ingredient of all successful programs is building collaborative alliances among family caregivers, other caregivers and service providers that better enable and empower caregivers. Likewise, interventions designed to educate parents and caregivers to facilitate their child's development, such as early intervention, positive parenting programs, positive behaviour support training etc. also serve to empower and strengthen the caregiver and the family. Our older caregivers reported these supports had been helpful during childhood and adolescence but were not a concern in adulthood when long-term future planning and financial security became paramount.

Despite a level of satisfaction associated with CSS initiatives, key areas of unmet need were identified that require additional resources and more flexible delivery options in languages other than English and that enable busy caregivers to attend. Furthermore, qualitative data revealed various families were struggling financially due to additional expenses for therapies and services as well as reduced income due to less availability for work related to their caring role. This is not unusual as people with ID and their families are often at greater risk of poverty with additional health problems and financial and social costs associated with caring for children with ID (Chou et al., 2007; Emerson, 2004, 2007; Larson et al., 2003). Addressing these issues is important as poverty contributes to poor parental and child health and well-being, further increasing the risk of parental stress and poorer coping and social outcomes.

There also appears to be a vacuum of understanding about the strengths and needs of a cohort of family caregivers who have failed to engage with CSS services. Logistics and timing of activities and events and language barriers may play a role but additional investigation into reasons for non-participation is required. Further research would benefit from using more accessible and alternative methods such as home interviews in the caregiver's language of choice.

The hub and spoke structure of the CSS was a feature staff and management considered beneficial to efficient service delivery. The spokes had the autonomy to deliver specific services tailored to local demand while the hub appears critical for resource funding and ongoing program improvement. This is especially important for implementing evaluation results, ensuring greater program flexibility, and obtaining resources necessary for extending services to meet unmet needs, in line with the Singapore Enabling Masterplan which details the government's focus on empowerment, resilience-building and community-based supports in the disability sector.

Given the important role caregivers play within the Singapore disability landscape, the findings lend support to the importance of caregiver support services identifying emerging needs and possibly integrating with case management from a family-centric perspective. The needs of the person with a disability and family should be assessed and tracked over time.

Limitations and future directions

The evaluation was part of a bigger study that also surveyed Family Quality of Life. This meant the length of time required to complete the surveys prevented the collection of additional relevant details such as the length of time involved with the CSS and the number of activities accessed. These data would have been helpful for further interpretation of results and should be included in future studies. Data on caregiver language preference were also not collected. The questionnaires had not been used previously in the Singapore context and no funding was available for language translation for written materials and surveys. Further, the scales had not been validated in the Asian context. However, qualified allied health professionals checked that the scales were suitable for use and appropriate for language and culture and participants were offered verbal translation services for survey completion and face-to-face interviews by staff fluent in their language. Although some translation services were used, data revealed some older parents had not received these translation services when completing the online surveys and it is unclear why not. Incomplete CSQ-8 questionnaires particularly may have been impacted by language difficulties. Comments indicated several older caregivers who spoke languages other than English did not understand some questions. This was further compounded by the CSQ-8 being completed last in a long survey that had multiple sections and respondents may have been fatigued. It is also possible that some caregivers, especially older ones may have been unwilling to criticise the organisation that was supporting their son or daughter. Efforts were made to assure respondents of privacy and anonymity. However, vulnerable people can fear reprisals and loss of services associated with making complaints or providing negative responses about services. Additionally, Singaporean culture is reported to still be hierarchical and influenced by Confucian thinking that puts a high value on harmonious and respectful relationships, consensus not conflict, filial piety, and obedience to seniors (Cultural Atlas, 2022). Importantly, consideration of these issues is foundational to the planning of all future research in Singapore.

Interviews were based on a convenience sample of those surveyed, with the assumption that theme saturation would be reached with the number of participants interviewed. This assumption appeared ratified by the convergence of data and thematic analyses.

CONCLUSIONS

Providing care to family members with ID across the lifespan can be rewarding but also highly stressful. Family caregivers needed and appreciated tailored supports that can empower them in the caregiving role. An important implication of this research is that findings inform policymakers and support agencies that the family, not only the person with ID, is an important factor and needs to be incorporated at the heart of the design and development of any inclusive community living and ageing-in-place model for Singapore. This is critical to delay and reduce institutionalisation.

ACKNOWLEDGEMENTS

We gratefully acknowledge the contributions of all the family caregivers and staff who took part in this study, and the organisation that supported the work. Open access publishing facilitated by The University of Sydney, as part of the Wiley - The University of Sydney agreement via the Council of Australian University Librarians.

FUNDING INFORMATION

This project was funded by the Movement for the Intellectually Disabled (MINDS) Singapore.

CONFLICT OF INTEREST

No potential conflict of interest was reported by the authors.

ETHICS STATEMENT

This research meets all ethical guidelines and legal requirements. It was approved by the University of Sydney Human Research Ethics Committee (HREC) Project Number 2017/338

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ENDNOTE

[1] In Singapore the term "aunties" is used to convey respect, affection and relationship at the same time, especially for older persons.

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SUPPORTING INFORMATION

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How to cite this article: Riches, V. C., O'Brien, P., Manokara, V., & Mueller, A. (2022). A study of caregiver support services: Perspectives of family caregivers of persons with intellectual disabilities in Singapore. *Journal of Policy and Practice in Intellectual Disabilities*, 1–15. https://doi.org/10.1111/jppi.12441