

## Promoting caregivers' well-being through MINDS Caregivers Support Services: An Evaluation 2017-2018.

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*"A caregiver – sometimes called an informal Caregiver - is an unpaid individual (for example a spouse, partner, family member, friend, or neighbour) involved in assisting others with activities of daily living and /or medical tasks".* NCSS, (2016)

Interest in caregiver support and family quality of life (FQOL) research has increased over recent years as more people with disability and especially intellectual disability (ID) live in the community with their families in preference to large or small residential group settings. There is also growing evidence of the positive and negative impact of having a family member with intellectual disability, the relationship and importance of this to whole family quality of life and the relevance of these issues for both assessment and intervention in social service delivery (Brown et al, 2010; Ho et al., 2013; Isaacs et al., 2007; Llewellyn et al., 2003; Roth & Brown, 2017, Werner et al., 2009).

Caregiving is mostly done informally and caregivers often report that their caregiving role provides meaning and fulfillment to their lives, although much research has focused on the level of stress and burnout associated with caregiving. In Singapore, a study undertaken by the National Council of Social Service (NCSS) found that caregiver participants were in constant survival mode, often lacked clarity on how social services worked, and frequently lacked the awareness, skills and resources needed for their caregiving role, as well as how to care for themselves. Moreover, the quality and level of assistance they received depended on the knowledge and experience of the providers they met (NCSS, 2016, p56). The 3rd Enabling Master Plan 2017-2021 (MSF, 2016) recognises that caregivers play a critical role in caring for persons with disabilities, and have three key concerns: preparing for the future, performing the role of a caregiver well and the need for self-care and respite.

The Movement for the Intellectually Disabled of Singapore (MINDS) established its MINDS Caregivers Support Services (CSS) and a coordinating Caregiver Support Service Centre (CSSC) in 2015. The aim was to support caregivers across transition points and development phases by offering a comprehensive range of support mechanisms. MINDS Caregivers Support Services has since offered a number of services, activities and programs to caregivers, and a range of workshops to address various caregiver needs.

MINDS engaged The Centre for Disability Studies (CDS) a non-profit organisation, affiliated with The University of Sydney, Faculty of Medicine and Health in 2017 to evaluate the Caregivers Support Service. The aim was to evaluate the degree to which MINDS the CSSC and the CSS have been able to impact (1) the Family Quality of Life of participating families, (2) the opportunities for social connections and social networking for families, (3) support to families through the training workshops offered by CSS, (4) the coping and resilience of caregivers, and (5) the degree to which the systems and processes of the CSS effectively and efficiently address the objectives of the service.

A mixed methodology approach was selected to enable both quantitative and qualitative data to be collected and analysed in the evaluation, and to provide a rich understanding of the key research aims and questions. A systems model framework was used to assist in the examination and identification of desired output and outcome measures and the contribution of various aspects of the system to their achievement or otherwise. Data consisted of caregiver responses to an online survey of family quality of life, coping competence and satisfaction with services received, and responses to a facilitated in-depth interview. Staff perceptions were gained through focus groups and interviews with management. Evaluation data from CSS activities and workshops were also reviewed. Ethics approval was gained through the University of Sydney Human Research Ethics Committee (HREC) processes.

### **Online Survey and Procedure**

MINDS invited caregivers to participate voluntarily in a survey through its email database of carers registered in the CSS program using ethics approved forms and procedures. Participants could choose to complete the survey questionnaires individually via mail, online, or in person at a location where the family member accessed the CSS. The surveys were administered in 2017 and consisted of three Instruments:

1. The Family Quality of Life Survey- short version 2006, (FQOLS-SV, -2006) (Brown, Brown, Isaacs et al., 2006) measures family quality of life in families who have a member with intellectual disability (ID) and addresses the degree to which family quality of life is enjoyable, meaningful, and supported by the types of resources that are important to family members, as well as the struggles faced by families. Specific domains are health, financial well-being, family relationships, support from others, support from disability related services, influence of values, careers, and preparing for careers, leisure and recreation, and community interactions. Six dimensions use a 5-point Likert scale with higher scores indicating higher levels. Two main outcome measures are Attainment (what families perceive they have been able to achieve in that domain) and Satisfaction (how families feel about their achievements). There are four explanatory measures of Importance, Opportunities, Initiative and Stability to help interpret the two main measures. Discrepancy measures between importance and attainment/satisfaction can also be calculated for each domain as well as a global FQOL and a global satisfaction score.
2. The Coping Competence Questionnaire (CCQ), (Schroder & Ellis, 2013) is a 12-item scale designed to assess resilience against helplessness and depression. The Total CCQ is an indicator of “coping competence” and scores can range from 12 to 72 with higher scores indicating greater resilience and coping.
3. The Client Satisfaction Questionnaire (CSQ-8) is an eight item, easily scored and administered measurement that is designed to measure client satisfaction with services and elicit caregivers’ perspectives on the value of services received. CSQ-8 Total scores can range from 8-32, with higher scores indicating greater satisfaction.

The semi structured in-depth interview involved questions on how the CSS has impacted upon FQOL, length of time associated with the CSS, type and frequency of services attended and received, goals in attending, satisfaction with services and preferences and ideas for enhancing or improving the services. A total of 36 consenting caregivers were interviewed by one of the MINDS Social Workers at a mutually convenient time at one of the 14 MINDS Centres.

The in-depth interviews involved a sample of 36 caregivers, 50% of whom reported they were fathers of the person with ID, 36.1% were mothers and 13.9% were the siblings. The sample was diverse and represented the cultural and religious diversities of Singapore. Ages of caregivers ranged from 31 to over 70 years.

MINDS Staff who had worked with caregivers through the CSS spokes (14 outlets) were invited to voluntarily participate in a Focus Group about the MINDS CSS. A total of 24 staff and one Board member each attended one of three Focus groups conducted at MINDS Headquarters. Data collected involved summary demographics (age band, length of service at MINDS, role with the CSS, and CSS Centre location) and key questions around what was Important to and Important for caregivers and staff, and the Four + One Questions from person centred thinking and planning: What have we tried? What have we learned? What are we pleased about? What are we concerned about? What should we do next? Additionally, one-on-one interviews were conducted with two MINDS staff in key management positions associated with the CSSC.

### **Workshop Evaluations**

A summary of collated results of activities and workshops conducted by the CSS was provided to CDS by the CSSC for the years 2016 - March 2018. A total of 18 training workshops had run over this two year period that addressed areas such as managing behaviour of concern, effective rule setting, developing daily living skills and greater independence, communication, transitioning to adult services and care planning. A total of 66 activities had been organised by the CSS over the period, including a number of networking, sharing, and family bonding activities, as well as sibling camps, leisure and recreation activities, and celebration and appreciation events. These all presented opportunities for social connections to be made or strengthened. These data were analysed and triangulated with data from the online surveys, the in-depth interviews, and staff focus groups and interviews.

The MINDS Caregivers Support Service (CSS) and initiatives (CSI) have been led and coordinated by a small team (CSSC) since 2015 that has been actively facilitating a range of activities, workshops and supports. A major strength of the evaluation and indeed the success of the program has been the engagement of fathers who have contributed their perspectives. This is unique as typically caregiver respondents have been mothers (Brown et al, 2010; Ho et al, 2013, Ncube, Perry & Weiss, 2018; Roth & Brown, 2017, Werner et al, 2009).

A total of 328 MINDS volunteer caregivers participated in the survey stage. Over three quarters of the sample were parents (77.7%), with the majority being mothers (51.4%), followed by fathers (25.1%), then siblings (n= 61 or 18.9%), while other caregiver respondents consisted of aunts and grandparents. The majority of families were two parent families (72.6%).

Caregivers were supporting a total of 335 family members with disability, 57% of whom were male and 43% were female. Ages ranged from seven to 64 years and the average age being 26 years (SD 12.2 years). The majority of persons with intellectual disability being cared for were living at home full time with their main caregiver (93%). Seven caregivers had two family members with intellectual disability. Conditions present other than ID involved speech and language disorders (n=161, 49%), behavioural conditions (n=129 or 39%), mood and anxiety (n=118 or 36%), and Autism Spectrum Disorder (n=51, 15.5%). Most family members required some level of disability related support ranging from a few aspects to almost all aspects of life. Significantly it was level of communication difficulty that caregivers rated most challenging, with 42% of caregivers reporting their family member was only able to communicate basic needs and wants and another 10% had no or little meaningful communication.

On the FQOL-SV 2006 survey, caregiver ratings for global family quality of life ranged from excellent (5) to poor (1). The average or mean score (M=3.03) indicated overall quality of life was good. Global satisfaction with family quality of life ranged from very satisfied (5) to very dissatisfied (1), with the majority (54%) satisfied (M=3.67).

It is noteworthy that all nine family life domains were rated as very important, with the most important domains being Health of the family (M=4.78), Financial well-being (M=4.57) and Family relationships (4.56). Although community interaction (M=3.2) was rated of lower importance than the other domains, it was still valued by caregivers who reported that barriers to inclusion continue in Singapore. Some caregivers reported experiencing stigmatisation, lack of acceptance and/or lack of understanding of persons with disabilities from the public, as well as personal social isolation.

Results on the Attainment and Satisfaction outcomes across the nine domains revealed that the majority of caregivers enjoyed some positive accomplishments and satisfaction. The overall mean attainment rating was good (M=3.35) and the overall satisfaction score was satisfied (M=3.54). Individual attainment and satisfaction results varied across the life domains. Family Relationships was rated highest of all domains for Attainment (M=3.95) and Satisfaction (M=3.98), followed by Health of the Family (Attainment M =3.74; Satisfaction M=3.64). The lowest attainment ratings were in the Support from Others domain (M=3.05) and the lowest satisfaction was in the Financial Well-Being domain (M=3.30).

Significant effects were found associated with family quality of life and satisfaction with FQOL according to gender, age, level of disability and level of communication of the person with ID being cared for. Behaviour of concern was not significant in the FQOL results, despite the fact that 39% of persons being cared for were identified as having a behavioural condition and interviews identified a few families were struggling with very specific behaviours. However, caregivers supporting males with ID had significantly higher attainment and satisfaction with family quality of life than caregivers of females with ID. This also applied to the area of Leisure and Recreation which was also rated more favourably by caregivers of males. Fathers rated Health of the family more positively than other caregivers, while mothers rated Family relationships higher than fathers or other caregivers. One parent families had poorer health ratings than two parent families. Poorer global FQOL scores were also evident among caregivers of adults aged 36-64 years across FQOL areas, although poorest scores for the Careers domain were found among caregivers of children below 16 years. Need of a higher level of disability related support and poorer communication of the person with ID was also associated with significantly poorer attainment and satisfaction scores in many family life domains. Respite across the age groups and in-home respite are examples of some services specifically requested.

Interestingly, the highest FQOL attainment and satisfaction scores recorded were in the area of Family relationships. Family relationships appear to be a critical area for caregivers and for people with ID themselves, with caregivers of persons with ID in other cultures and countries also rating this domain most highly (Brown, 2008, 2013; Werner, Edwards, Baum, Brown, et al., 2009). Strengthening family relationships is one area in which the CSS has provided a number of workshops and family bonding sessions as well as sibling camps. Numerous comments from caregivers and staff alike indicated the positive benefit and value of these supports, which no doubt contributed to the positive attainment and satisfaction ratings reported.

Little or no discrepancy between importance and attainment/satisfaction mean scores would indicate a high level of FQOL in that people have and are satisfied with aspects of life that are important to them. Conversely, a large discrepancy would indicate much lower FQOL in that people do not have and are not satisfied with aspects of life that are important to them. Caregivers surveyed obtained an overall discrepancy score of 0.69, indicating moderate concern still exists across the nine family life areas. Discrepancy scores fell in the serious range in the areas of Financial well-being ( $D=1.21$ ) and Health of the family ( $D=1.09$ ). Areas of moderate discrepancy were recorded for Disability related services ( $D=0.85$ ), Family relationships ( $D=0.59$ ), Careers ( $D=0.55$ ), Support from other people ( $D=0.54$ ) and Values ( $D=0.53$ ). Leisure fell in the range of possible concern ( $D=0.38$ ), and the only domain rated of little concern was Community interaction ( $D=0.10$ ).

Data from interviews with both caregivers and staff identified that the supports provided by the CSS have contributed to better family QOL and satisfaction. Nevertheless, the discrepancy between importance and attainment/satisfaction was substantial, especially for Financial well-being and Health of the family. One caregiver explained: "If I don't have good health, I cannot take care of (X). If no money, no need to say, more stress definitely. Only with regular and steady income, good health, you can then think about other things, leisure, go holiday etc." Future planning workshops have been provided but some caregivers who were interviewed still identified an ongoing need for support in this area, especially as parents age or pass away. Appreciation was expressed regarding some financial assistance provided to attend various programs but it was also apparent that some families face additional disability related costs for therapies, travel etc., which can place them under stress. International research has clearly identified that people with intellectual disabilities and their families are at greater risk of poverty and that poverty can also be associated with poor parental and child health and well-being, which can further increase the risk of more dysfunctional parenting practices and poorer social outcomes (Emerson 2004, 2007; Hatton, Azmi, Caine, & Emerson, 1998; Larson, Lakin, & Anderson, 2003).

Serious level discrepancy scores were also apparent for Support from Disability related services ( $D=1.09$ ), and Support from others ( $D=0.91$ ), meaning there are still gaps evident with some caregivers having serious unmet support needs. This was in spite of a significant positive relationship being found between satisfaction with disability related services, satisfaction with family quality of life and higher satisfaction with CSS services (CSQ-8 scores), indicating there was considerable satisfaction with CSS initiatives and services ( $F(4,284)=12.62$ ,  $p<0.001$ ). It was clear that many caregivers had gained considerably from family bonding and networking opportunities, sibling camps and other support initiatives provided through the CSS. Caregivers highlighted the mutual benefits gained from talking with and supporting one another, as well as support gained from staff and CSS services. While it was clear that CSS staff had made attempts to engage a greater number of caregivers in CSS activities and workshops over time, the challenge is that a number of caregivers have not participated or have been unable to participate, and these families may require a broader range or type of supports, and /or consideration of logistical arrangements to better suit their needs.

The MINDS caregivers' FQOL results showed similar trends to results found among caregivers FQOL in countries including Canada, Poland and Israel. Although some individual scores differ slightly with some higher and some lower, the Singapore caregivers' family quality of life and satisfaction levels were as positive and comparable to caregivers in other countries, with more similarities than differences apparent (Brown, et al., 2010; Ho, et al., 2013; Roth & Brown, 2017; Werner et al., 2009).

Coping competence and resilience among participants as measured on the Coping Competence - Dealing with Stressful Situations (CCQ) varied widely, from very poor to excellent, with the majority gaining good coping and resilience scores. There was a consistent trend with lower coping competence scores associated with lower FQOL ratings and greater dissatisfaction with FQOL. Lower coping competence was also associated with lower Attainment scores in six domains: Family relationships, Support from other people, Values, Careers, Leisure and recreation and Community interactions; as well as lower Satisfaction in the Health, Family relationships, Support from other people, Leisure and recreation and Community interactions domains. Poorer coping was also found among caregivers supporting older adults and children, as distinct from young adults (17-35 years).

It would appear that a number of the CSS initiatives were both educational and supportive of mental health and better coping and resilience. Both interview and focus group data identified caregiver support services have had a positive and beneficial effect, with bonding and networking sessions and sharing opportunities in particular nominated as helpful in relieving stress and assisting caregivers to feel understood and no longer isolated and alone. Knowledge gained from workshops and staff support had enabled other caregivers to better cope with and manage behaviour. Nevertheless, the CSS could consider enhancing its range of strategies and services to further reduce stress among vulnerable families.

Caregivers' level of satisfaction with MINDS supports and services, as measured on the Client Satisfaction Questionnaire (CSQ-8) ranged from dissatisfied to very satisfied, with the average or mean of 23.4 indicating mostly satisfied. Highest rated items revealed caregivers were happy to recommend CSS services to friends in need of similar help, were satisfied to return to MINDS CSS for further support, and that services had helped them deal more effectively with problems. However, responses on the extent to which services had met their needs varied and was the lowest rated item, as 36% of caregivers responded that only a few of their needs had been met, and 34% were neither satisfied or dissatisfied with the amount of help received. Interview data provided further corroborating evidence for satisfaction, as 81% of caregivers interviewed rated overall satisfaction with the MINDS CSS as "mostly satisfied" or "very satisfied", 11% of all interviewees answered they were indifferent or mildly dissatisfied with the services and no interviewee rated "very dissatisfied".

Prime goals and motivations to participate in MINDS initiatives and services nominated by caregivers involved bonding/networking opportunities, interacting with other families and gaining mutual support from one another and learning skills and knowledge related to the client's life stages, support needs, and long term care planning through the various workshops and sessions. Those who attended were highly appreciative of the activities and workshops, which caregivers reported were extremely helpful in facilitating mutual social and emotional support and transferring required knowledge and skills e.g. "Thank you for being there when needed though it's not easy. Lots of appreciation to each and every member of the MINDS family". Staff also reported many caregivers were highly appreciative of the workshops and other services offered, that attendance at these events often improved communication between staff and caregivers and among caregivers themselves and their families, and ideas tended to be more forthcoming once caregivers engaged with the initiatives.

Managers identified CSS achievements included a broadening engagement to include extended family members such as grandparents and aunts and uncles, the value of sibling camps and facilitation of networking opportunities and social connections among caregivers. Staff identified themes most important to and for caregivers consisted of (1) the personal support needs of caregivers, including social and emotional support from family, informal supports and formal agencies and services, respite, self-care, health and ability to manage their stress; (2) specific supports provided to the family by the CSS, involving recreation and leisure activities, family bonding and participation in various activities and workshops; and (3) provision of knowledge, information and resources about issues related to caregiving. Key topics included future planning and long-term care planning; finances and financial capability; schemes and benefits such as Deputyship; understanding the needs of their child and skills to manage ADLs, communication, behaviour etc. and the person centred approach for their child/family member.

Higher satisfaction with services was significantly related to higher FQOL and higher satisfaction with FQOL, and higher satisfaction with disability related services. Lower satisfaction with services was found associated with the level of communication of the person being cared for. Caregivers supporting persons whose communication was limited to basic needs and wants had lower satisfaction levels than caregivers where communication was good or almost non-existent. A linear multiple regression analysis revealed a significant relationship existed between Global FQOL and overall satisfaction with services as measured by the CSQ-8 Total, age group of family member with disability, level of communication of person with disability and coping competence (CCQ Total),  $F(5,210)=17.05$ ,  $p<0.001$ , and these variables together explained 29% of the variance in Global FQOL.

The major issue signalled by both caregivers and staff concerned the fact that CSS support services are typically offered during normal working hours. Many caregivers indicated they cannot attend due to their own work commitments and/or the need for respite or child-minding and would prefer events to be held after hours such as night time or weekends and at locations close to home. Language barriers were also raised as significant for some families. Clearer information about the benefit of the services and/or a different set of activities and supports may also be required by some who have not engaged with the initiatives offered to date. Several caregivers also explained their struggles coping in the caregiving role with issues including stress, the need for respite and/or after school care and specific difficulties with transport or finding the right intervention and supports related to behaviour of concern or epilepsy. Suggestions on how to address these logistics was the major theme concerning how the CSS can be improved.

Additional positive suggestions were forthcoming from caregivers and staff that could be used to further improve and enhance services. Particular areas that require further investigation with the possibility of extending support are among families where the disability support needs are high and complex, especially in the area of communication. Staff further recognised various areas for program improvement that aligned with caregiver responses, especially around the fact that a substantial number of caregivers have not participated to date, and the need to clearly identify unfulfilled needs and how better to engage a broader clientele.

The coordinating role of the CSSC appears essential for ensuring ongoing accountability and program improvement, and continuity of the program is a major concern with the imminent cessation of The Tote Board Enabling Lives Initiatives (TBELI) funding. CSSC management interviews emphasized the importance of operating according to a hub and spoke model, based upon the vision of support services enhancing the well-being of families, developing family relationships, as well as reducing stress. The CSSC is the hub that can coordinate and monitor activities and supports while and the spokes (i.e. the various MINDS centres) have the autonomy to match carer need to tailored services, and this is an area that can be further extended and customised to ensure more caregivers' needs are addressed that take into account the differing age, communication and levels of ability of persons with intellectual disabilities involved. The hub also has the responsibility of ensuring that resources are available and that a range of customised and relevant activities are provided to caregivers, while staff also require managerial and team support, as well as critical professional development.

Staff training is an ongoing responsibility for the organisation as a whole, but there can be specific requirements in relation to caregiver support services that are important to ensure staff remain relevant, meet practice standards and provide supports according to current evidence-based best practice. Staff identified that it is important they possess the personal knowledge, skills and attributes to support caregivers effectively, that they have relevant information and knowledge to impart to caregivers, that they themselves manage boundaries well and engage in self-care and work together in teams supporting one another. Specific professional development required involves updates and changes such as the move to in-home respite that is particularly relevant for current best practice. Another is training staff in the knowledge and skills required to facilitate caregivers' access to and use of community connections and natural supports in families and local communities.

Funding to ensure continuity of the present structure of the Hub and Spoke model is required. It is also recommended that outcome measures be introduced into the program that address coping and resilience amongst carers as well as Family Quality of Life and satisfaction measures that could further contribute to ongoing program improvement.

The evaluation identified that caregiver support initiatives provided since the inception of the CSSC in 2015 have primarily been activities that provide emotional and social support, fostering of informal networks, and leisure and recreation activities, as well as training workshops to provide information and increase skills and competence among caregivers.

The overall impact of the MINDS Caregivers Support Services has been positive, with many participating caregivers expressing sincere appreciation for the supports provided and significant impact noted across the areas investigated.

Data from all sources accessed in the evaluation attest to high levels of satisfaction and improvements in coping and resilience noted among most participants. Networking and bonding opportunities, the provision of additional skills and knowledge gained through workshops and appreciation for support given by staff across the CSSC and the spokes featured among the key benefits raised by interviewees. However, a small number of caregivers were dissatisfied with the quality of their lives and need additional or different supports from those offered, as identified in the data. A number of suggestions for performance improvement were also gained from caregivers and staff that could further enhance the services and supports provided.

Overall, MINDS caregivers involved in the study generally had much better outcomes in terms of family quality of life, resilience and satisfaction than the situation identified in the 2016 NCSS study of Singapore carers, which reported caregivers were in constant survival mode.

1. Ongoing secure funding is sourced to ensure continuation of the hub and spoke model for the MINDS Caregivers Support Centre (CSSC) caregiver support services and initiatives.
2. A range of relevant customised activities are developed and extended for caregivers of persons with intellectual disability who are in both the older and younger age brackets, and whose children or family members have higher levels of communication and disability support need.
3. Relevant customised activities are developed and offered to fathers

4. Professional development and training is provided to staff to ensure relevant, up to date models of care and evidence-based best provision across both services and support initiatives including: Mindfulness and resilience building practices, respite, in-home respite and facilitation and use of natural supports and community connections.
5. Logistics of the various activities and supports be extended with some activities offered at night and/or weekends to facilitate attendance by working caregivers, with additional support resources investigated such as child-minding, and interpreter services for languages e.g. Tamil and Mandarin.
6. The definition of carer is extended to include foreign worker and adult sibling.
7. Consideration is given to partnering with other services and/or advertising and offering sessions that address specific challenges that may involve small numbers of MINDS caregivers more widely across the Singapore disability community.
8. The CSSC routinely collect data and report on outcome measures involving family life areas, satisfaction and coping and resilience of caregivers.
9. Explore the range of suggestions provided by staff and caregivers regarding ongoing and future service delivery, such as: advocacy, information provided via apps etc.; extending the CSSC opening hours for a caregiver drop-in service from 11am -10pm; as well as specific support needs of ageing caregivers.