

Measuring the Family/Friend Caregiver Experience in Ontario: Pilot Study Results

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)
University of Toronto

Version 2.0 (Revised August 13, 2021)

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Acknowledgements

The project team would like to acknowledge and thank the many individuals and organizations that contributed to the development of the Family/Friend Caregiver Survey. The members of the expert advisory committees include the following:

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Project Partners & Funders

Funding for the Family/Friend Caregiver Project was provided by the Ministry of Health and Long-Term Care through the 2013-16 Health Services Research Funding initiative. The project was part of a larger study led by Dr. Walter Wodchis at the University of Toronto's Health System Performance Research Network (HSPRN). We would like to thank HSPRN for their ongoing support, in particular the contributions of Kevin Walker, Research Associate, and Kayla Song, Research Assistant.

Main Messages

- Supported by a multi-stakeholder Advisory, our objective was to develop and test an online survey of the family/friend caregiver experience in Ontario that would provide essential information to government for policy planning and decision-making.
- The Family/Friend Caregiver Survey was pilot tested with over 300 Ontario caregivers. A supplemental survey was also developed and tested for caregivers of children and youth with mental health and/or addictions problems.
- Results reveal the emotional toll of caregiving, with the majority of respondents identifying emotional support as one of the most difficult and time consuming tasks they perform for their care receivers. Caregivers also identified their role as having a significant negative impact on their emotional well-being.
- A large percentage of caregivers from our pilot study were working full-time or part-time, while also providing 20 or more hours of care per week, for more than five years. A picture of substantial demand emerges, in terms of obligations and roles for Ontario caregivers.
- The impact of caregiving on work and/or school responsibilities was significant, with one-third to one-half of respondents indicating they frequently think about caregiving or use work/school time to perform caregiving tasks. One-third also reported receiving little employer support.
- Difficulty in accessing services was identified as a key barrier to caregiver service use, as were financial constraints. For mental health services, stigma was identified as a significant factor preventing service use.
- Care receiver reluctance was selected as a principal reason for not using a particular service for three of four care receiver services (home-based care, long-term care, recreation/social support).
- A large percentage of caregivers reported experiencing financial hardship because of their caregiving responsibilities. Given that a quarter of this group is 65 or older, this finding raises concerns about the impact of caregiving on retirement.
- Caregiver respondents found the online survey both feasible and acceptable; the survey yielded information that was relevant to a variety of stakeholders, including government, caregiver organizations, and individual caregivers.
- Based on pilot findings and external stakeholder feedback, a number of conclusions and future directions emerged. Next steps include using pilot results to finalize the survey and initiate ongoing data collection.

Background

Family and friend caregivers are critical to Canada's health care system, contributing an estimated economic value of \$25 billion annually (Hollander, et al., 2009). The impact of this contribution is both personal and societal. Results from the 2012 General Social Survey on Caregiving and Care Receiving (Statistics Canada, 2012) reveal that 28% of caregivers have young children living at home; 27% provide care for more than one person; and 44% provide care during their peak earning years (Sinha, 2013). Integrated policies are needed to support this valuable resource but systematic information from caregivers to inform policy is lacking. The objective of this study was to develop and pilot test an online survey to collect systematic and relevant feedback from diverse Ontario caregivers.

Method

An integrated knowledge exchange process guided the study, with extensive involvement of an interdisciplinary Knowledge User Advisory that included representation from government, family caregivers, service providers, caregiver organizations, and researchers. The Advisory guided key study decisions and provided input on the following:

- 1) Government, particularly at the provincial level, was identified as the primary target audience. This decision resulted in the survey going beyond the traditional assessment of caregiver needs to focussing on the relationship between these needs and the services and supports provided at the provincial level.
- 2) The survey would be designed to be **general** – that is, relevant to all family/friend caregivers, not just those providing care for people with specific illnesses or conditions.
- 3) Specific illnesses or conditions could be addressed using short modules that would supplement the general survey. (Such a module was developed for caregivers of young people with mental health and/or addictions problems but is not described in this report.)
- 4) In keeping with these decisions, key survey domains were selected, informed by a review of the scientific and grey literature and by consideration of two theoretical frameworks: caregiving as a personal commitment (e.g., stress-burden literature) and as an unpaid labour force (e.g., occupation demand literature). This process resulted in the identification of five domains: caregiver 'work' demands; 'work' impacts; resources/supports; attitudes and culture; and uncertainties (see Appendix A).
- 5) Survey questions were developed within each identified domain, selecting from existing validated tools and creating new questions for identified gaps. In addition, some items were added to allow comparison between the survey and the 2012 General Social Survey on Caregiving and Care Receiving (Ontario data only; Statistics Canada, 2012).
- 6) The survey was pilot-tested in three phases: i) expert review and initial testing by Advisory members; ii) recruitment of 30 caregivers for cognitive face-to-face interviews, and survey revisions; and, iii) recruitment of 300 Ontario caregivers for online testing and final survey revisions.

The remainder of the report provides pilot study results for the online testing with a convenience sample of 300 Ontario caregivers.

Results

Summary

Caregivers who completed the online survey indicated that it was both feasible and user-friendly. However, 7% of respondents identified the survey's completion time, averaging 43 minutes, as problematic. Despite its length, the majority of caregivers who started the survey (61%) completed it (N=302), and 90% of those took the time to provide lengthy responses to the last three qualitative questions.

Our convenience sample differed from provincial caregivers in a number of ways, based on the Ontario General Social Survey (GSS-ON) population (see Exhibits 1-4, 15b). For example, our respondents were older and spent more time caregiving (43.4% spent 20+ hours caregiving vs. 13.4%, GSS-ON), and had lower self-rated health (9.6% reported being in excellent health vs. 21.8%, GSS-ON). Also, our sample was more likely to be receiving caregiver-related federal tax credits (30.5% vs. 4.1%, GSS-ON). The top three health problems of care receivers were mental health/behaviour (31.1%), dementia-related (16.2%), and neurological disorders (12.6%) compared with aging, cardiovascular, and cancer for the GSS-ON group.

Tasks identified by caregivers as the most time consuming as well as the most difficult to perform included emotional support (68.5%/36.4%) and managing behaviour (40.7%/42.9%). The most commonly used service by caregivers was “education and support services” (49.0%), while “respite” (28.5%) was the most needed but unused. The number one service used by care receivers was “health and other therapies” (76.2%), with “recreation/social support” (30.1%) and “system navigation” (24.5%) identified by caregivers as the most needed but unused services.

The next sections review the survey results in more detail.

SECTION A: Description of Survey Respondents

Exhibit 1: Demographic Information

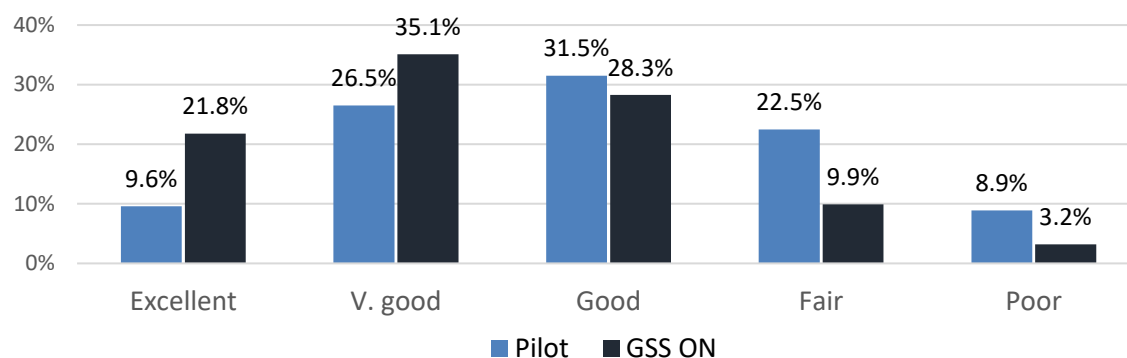
Caregiver Characteristics	Pilot (%)	GSS-ON (%)
Female	81.5	53.7
Marital Status		
Married	68.2	64.4
Single	11.6	27.0
Widowed/divorced/separated	18.8	8.5
Caregiver Age		
Under 25	0.7	16.3
25-44	21.2	29.7
45-64	52.0	42.2
65+	24.2	11.7
Care Receiver Age		
Under 25	21.5	6.7
25-44	17.5	6.2
45-64	19.5	18.5
65+	41.4	62.6

- Compared to the Ontario portion of the GSS, the pilot sample was:
 - More likely to be female
 - More than twice as likely to be widowed, divorced, or separated
 - Older and providing care for a younger care receiver
- Other demographic information:
 - 72.5% of all respondents were born in Canada
 - Almost 80% live in urban areas
 - 84.4% completed post-secondary education; 33.4% college/trade school degree or some university, 26.8% an undergraduate degree, and 24.2% a graduate degree

Exhibit 2: Main Health Condition of the Care Receiver

Health Condition	Pilot (%)	GSS-ON (%)
Aging/old age	7.9	27.1
Cardiovascular	4.3	9.3
Cancer	3.6	9.9
Mental health/behaviour	31.1	6.6
Dementia-related	16.2	5.9
Neurological	12.6	5.3
Developmental/intellectual	4.6	2.0
Addictions	2.0	0.4
Other	< 5% each	<5% each

- 27.1% of GSS-ON caregivers identified aging/old age as their care receiver's main problem. By contrast, pilot respondents selected mental health/behaviour as the most common problem (31.1%), followed by dementia-related disorders (16.2%) and neurological disorders (12.6%).
- These results may reflect our recruitment strategy, which included advisory board members and community organizations with an interest in mental health and was based on a snowball technique, where existing research participants recruit future participants.

Exhibit 3: Self-Rated Health of Caregivers

- 9.6% of pilot respondents reported being in excellent health compared to 21.8% in the GSS-ON group.
- Overall, our pilot respondents have a lower perceived level of health than the provincial sample.

Self-rated Health:

A question on self-rated health is included in many of Statistic Canada's household surveys and is a reliable indicator of health-related quality of life.

SECTION B: Caregiving Work Demands & Impacts

Exhibit 4: Average Hours per Week Spent Caregiving

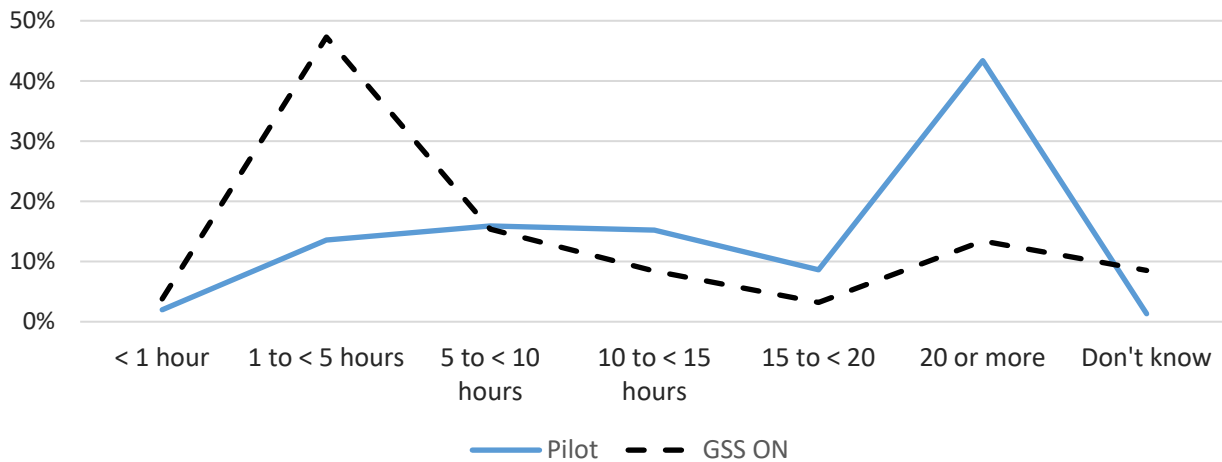
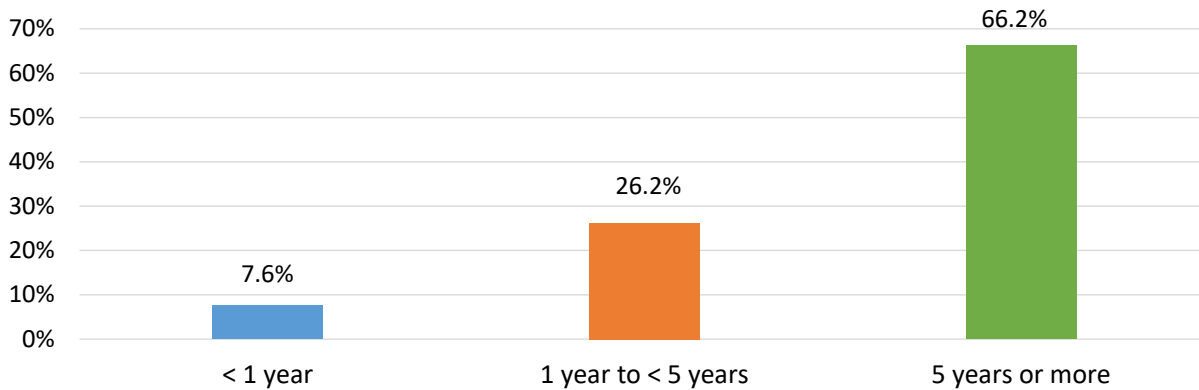


Exhibit 5: Length of Time Caregiving



- Compared to the GSS-ON, pilot caregivers average far more hours per week caregiving:
 - 47.3% of GSS-ON caregivers spent between one to less than five hours per week caregiving versus 13.6% of our pilot sample;
 - 13.4% of the GSS-ON sample spent 20 hours or more on care-related activities, versus 43.4% of pilot caregivers.
- 66.2% of the pilot respondents have been providing care for five years or more.
- Main activity of respondents (not shown): 40.7% working full-time; 12.3% working part-time.

Key Finding:

A large percentage of caregivers are working full-time or part-time, while also providing 20+ hours of care for five years or more. A picture of substantial demands emerges, in terms of obligations and roles for Ontario caregivers.

Exhibit 6: Oberst Caregiving Burden Scale Results

©Oberst Caregiving Burden Scale, American Association of Neuroscience Nurses, 2004 (Bakas, et al., 2004)

6a: Tasks with Most and Least Time Spent

Great/Large Amount of Time (%)		No Time (%)	
Emotional support	68.5	Assist w/ walking, etc.	48.3
Monitoring symptoms	44.0	Personal care	41.4
Transportation	44.0	Arrange care while away	40.7
Managing behaviour	40.7	Medical treatments	38.7
Household tasks (e.g., laundry)	39.1	Communication	20.5

6b: Tasks with Most and Least Difficulty

Extremely/Very Difficult (%)		Not Difficult (%)	
Arrange care while away	49.2	Medical treatments	48.1
Managing behaviour	42.9	Tasks outside home (e.g. shopping)	36.8
Emotional support	36.4	Household tasks (e.g., laundry)	29.6
Communication	30.8	Planning activities for care receiver	25.3
Seek/give information	27.8	Assist w/ walking, etc.	25.0

- 68.5% of our caregivers identified emotional support or “being there” as a task that required a great amount of time. Monitoring symptoms (44.0%) and transportation (44.0%) were the next two most time consuming tasks identified.
- The tasks with the highest rating in terms of difficulty were arranging care while the caregiver was away at 49.2% and managing behaviour at 42.9%.
- 48.1% of respondents did not find medical or nursing treatments difficult to perform. This suggests that this sample of caregivers have a reasonable partnership with the formal health care system and/or are not caring for people with medically complex problems.

Oberst Caregiving Burden Scale is a validated scale measuring time spent and difficulty related to 14 caregiver tasks. For time, the 5-point Likert scale ranges from “a great amount” to “none”, while for difficulty, the scale ranges from “extremely difficult” to “not difficult”.

Exhibit 7: Bakas Caregiving Outcomes Scale Results

©Bakas Caregiving Outcomes Scale, Bakas, T., 2007 (Bakas, et. al., 2006)

7a: Positive, Neutral, and Negative Aspects of Caregiving

Positive Change (%)		No Change (%)		Negative Change (%)	
Relation w/care receiver	30.8	Self-esteem	42.4	Emotional well-being	80.8
Relation w/family	17.9	Financial well-being	33.4	Energy level	79.5
Self-esteem	16.2	Physical functioning	31.8	Time for family activities	74.8
Ability to cope w/stress	11.6	Relation w/friends	29.1	Ability to cope w/stress	73.8

- The aspects of their lives that caregivers most commonly reported as negatively impacted by caregiving included emotional well-being (80.8%), energy level (79.5%), time for family activities (74.8%), and ability to cope with stress (73.8%).
- Areas identified as neutral or experiencing no change due to caregiving included self-esteem (42.4%), financial well-being (33.4%), physical functioning (31.8%), and relationship with friends (29.1%).
- There were some positive changes noted by caregivers, namely improved relationships with both the care receiver (30.8%) and other family members (17.9%).

Bakas Caregiving Outcome

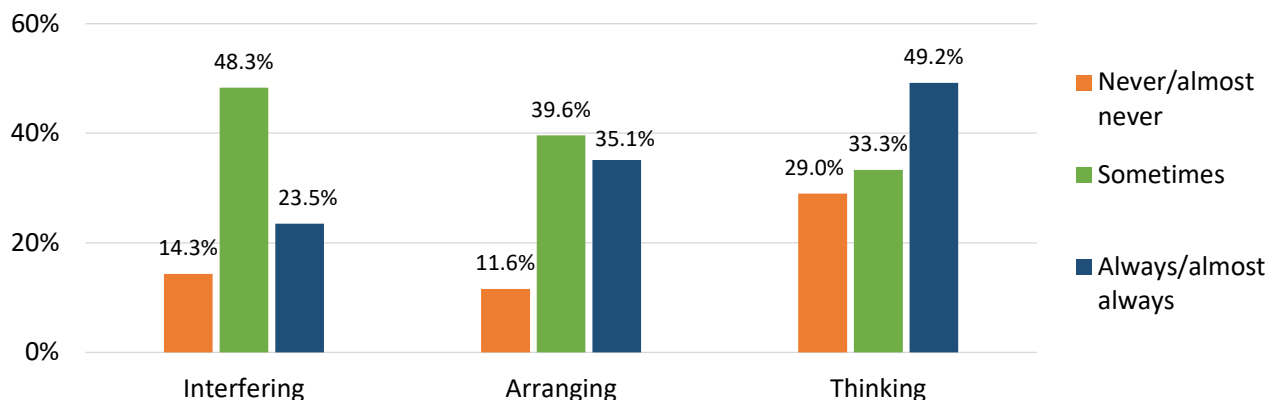
Scale is a 15-item validated scale used to measure the positive and negative aspects of caregiving. Respondents select the number that best represents the degree of change experienced because of providing care from -3 “changed for the worst” to +3 “changed for the best”. Zero represents “no change”.

Key Finding:

Data from the Oberst and Bakas Scales reveal the emotional toll of caregiving, with the majority of respondents identifying emotional support as a task that is both time consuming and difficult to provide to care receivers. Caregivers also identified their role as having a significant negative impact on their own emotional well-being.

Exhibit 8: Work/School Interference Scale Results

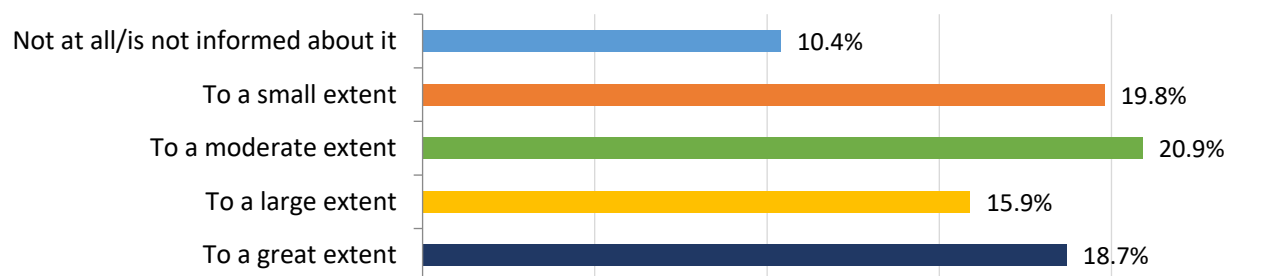
© Work-Family Interference Scale, Carlson & Frone, 2003 (Carlson, et al., 2003)



- **Interfering:** 23.5% reported that caregiving always/almost always interferes with work or school responsibilities (e.g. arriving on time, accomplishing daily tasks, working overtime).
- **Arranging:** 35.1% reported that they always/almost always use work or school time to perform caregiving-related activities.
- **Thinking:** 49.2% indicated that they always/almost always think about caregiving tasks they need to accomplish at home while at work or school.

Work-Family Interference Scale Three modified items from this scale were included to measure the impact of caregiving on work/school, with respect to productivity and missed time.

Exhibit 9: Employer Support for Caregiving Role



- 34.6% of caregivers reported that their employers were supportive of their caregiving role to a large or great extent, while another 20.9% indicated moderate support.
- 30.2% reported employer support to a small extent or none at all. In the latter case, some caregivers had not informed their employer of their caregiving role.

Key Finding:

The impact of caregiving on work and/or school responsibilities is significant, with one-third to one-half of respondents indicating they frequently think about caregiving or use work/school time to perform caregiving tasks. One-third also report little employer support.

SECTION C: Services, Supports, and Barriers

Exhibits 10 and 11 report on services and supports for the caregiver.

Exhibit 10: Caregiver Service Use and Met Need

Service	Education/ Support (%)	MH Services (%)	Respite (%)
Used	49.0	46.0	22.5
Extent of Met Need			
A great deal	18.2	16.5	22.1
Fair amount	28.4	25.2	22.1
Somewhat	43.9	49.6	52.9
Not at all	10.8	11.5	4.4

- Caregiver education and support services were the most used service at 49.0%, followed by mental health services (46.0%), and respite services (22.5%).
- When asked to rate the extent to which a service met their needs, caregivers selected “somewhat” most frequently, indicating that there is room for improvement across all three types of services.

Caregiver Services:

1. **Education/ support services** (caregiver support groups, educational seminars, faith-based groups, one-on-one advice, etc.)
2. **Mental health services** (psychologist, psychiatrist, other individual/group counselling, etc.)
3. **Respite services** (in-home or out-of-home for short-term or extended break)

Exhibit 11: Caregiver Service Non-use and Barriers

Service	Education/ Support (%)	MH Services (%)	Respite (%)
Needed but not used	20.2	15.6	28.5
Barriers to Service Use			
Hard to access	49.2	31.3	32.6
Financial issues	19.7	35.4	37.2
Unable to/felt guilty leaving care receiver	9.8	14.6	31.4
System confusing	32.8	18.8	20.9
Afraid (stigma)	8.2	18.8	3.5
Services inappropriate	19.7	12.5	20.9

- **Respite** was the most needed but not used service (28.5%):
 - Main barriers were financial issues, difficulty accessing services, and feeling unable to or guilty about leaving the care receiver.
- **Education/Support** services were needed but not used by 20.2% of caregivers:
 - Barriers included difficulty accessing services (49.2%), financial issues (19.7%) and inappropriate services (19.7%).
- **Mental health** services were identified by 15.6% of caregivers as needed but unused:
 - Barriers included financial (35.4%) and access (31.3%) issues.
 - “Fear of what people would think” was selected by 18.8% of respondents as a barrier to mental health services, indicating a sense of stigma related to these services.

Barrier Definitions:

- Financial issues - services too expensive, not covered or only partially covered by insurance, etc.
- Hard to access - not available, time/location inconvenient, long wait list, not culturally appropriate, language barriers, applied but turned down, etc.
- System confusing - did not know what was available or where to go, etc.

Key Finding:

Access was a key barrier for all three caregiver services, while financial issues were significant in two of the three. Stigma plays an important role in preventing mental health service use.

Exhibits 12 and 13 report on services and supports for the care receiver.

Exhibit 12: Care Receiver Service Use and Met Need

Service	Health & Other Therapies (%)	Home-based (%)	System Nav. (%)	Recreation/ Soc.Support (%)	Long-term Care (%)
Used	76.2	38.1	31.8	33.8	17.2
Extent of Met Need					
A great deal	22.2	31.3	31.3	23.5	26.9
Fair amount	30.0	31.3	19.8	30.4	40.4
Somewhat	34.3	33.0	40.6	44.1	26.9
Not at all	8.3	4.3	6.3	2.0	5.8

- The number one service used by care receivers was health and other therapies at 76.2%, followed by home-based services (38.1%) and recreation/social support (33.8%).
- As with caregiver services, when asked to rate the extent to which a service met care receiver needs, “somewhat” was selected most frequently across four services, indicating room for improvement. The exception was long-term care where the most frequent rating was “fair amount.”

Care receiver services include:

1. **Health & other therapies** (e.g. physician, physiotherapist, occupational therapist, mental health services, autism services, residential treatment services, etc.)
2. **Home-based** services (e.g. personal support worker, Meals-on-Wheels, nursing services, homemaker or home maintenance, etc.)
3. **System navigation** (e.g. CCAC, formal system navigator, library services, etc.)
4. **Recreation & social support** (e.g. day programs, social clubs, peer support activities, etc.)
5. **Long-term care** (e.g. long-term care facility, retirement home, nursing home, supportive housing, group home)
6. **Education-related** services (MH/A module only; not shown) (e.g. psychological testing, assistive devices (hardware/software), counselling, tutoring, etc.)

Exhibit 13: Care Receiver Service Non-use and Barriers

Service	Health & Other Therapies (%)	Home-based (%)	System Nav. (%)	Recreation/ Soc.Support (%)	Long-term Care (%)
Needed but not used	6.3	14.6	24.5	30.1	13.9
Barriers to service use					
Care receiver reluctant to use	*	43.2	31.1	67.0	45.2
Hard to access	*	38.6	40.5	34.1	50.0
System confusing	*	20.5	40.5	13.2	11.9
Financial issues	*	31.8	17.6	26.4	26.2
Poor quality	*	15.9	14.9	14.3	9.5
Guilty using service	*	9.1	0.0	3.2	11.9
Afraid (stigma)	*	0.0	2.7	2.2	4.8

**Data suppressed for Health & Other Therapies due to small numbers*

- **Recreation and social support** were the services that were most needed but not used at 30.1%. The primary barrier was the care receiver's reluctance to use those services (67%).
- **System navigation** was the second most needed but not used service at 24.5%:
 - Main barriers included a system that was hard to access (40.5%) and confusing (40.5%).
 - Navigation services, designed to help caregivers navigate a confusing system, are confusing and inaccessible in and of themselves.
- **Home-based services** was selected next as a needed but not used service (14.6%):
 - Care receiver reluctance was the most selected barrier at 43.2%, followed by hard to access (38.6%).
- **Long-term care** was selected by 13.9% as a needed but not used service:
 - Hard to access (50.0%) and care receiver reluctance (45.2%) were the top two barriers.

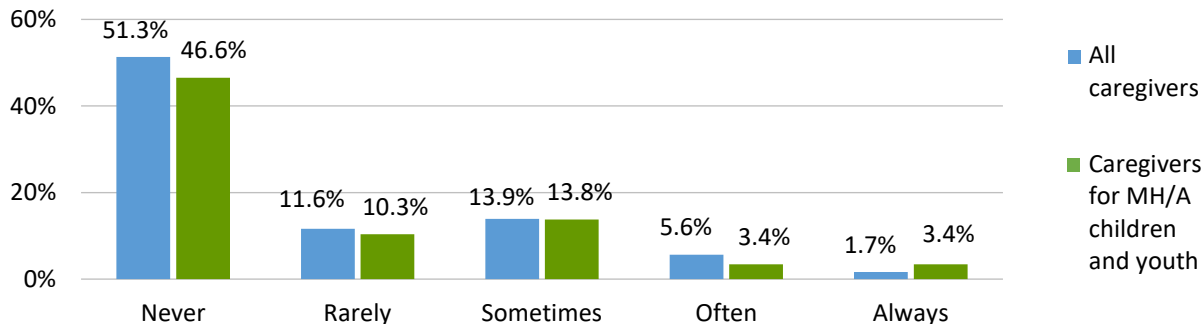
Key Finding:

For three of four services, (home-based, LTC, recreation/social support), "care receiver was reluctant to use services" was selected as a principal reason for not using a particular service.

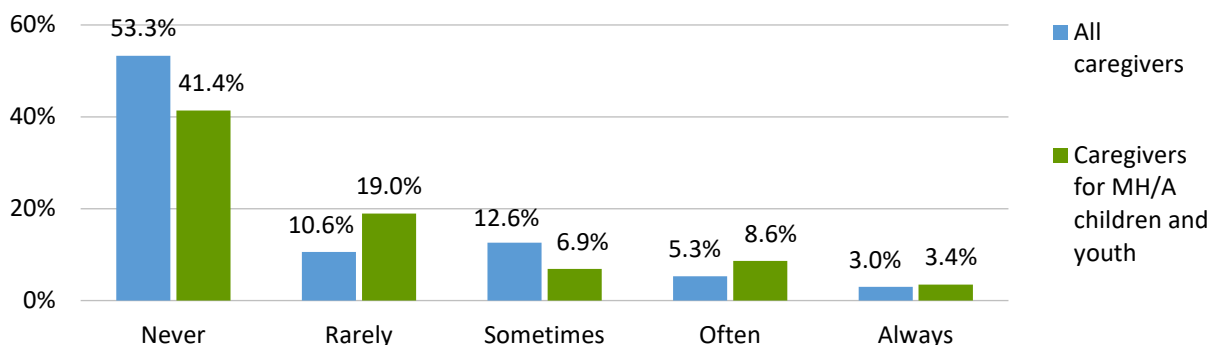
SECTION D: Other Barriers to Caregiving

Exhibit 14: Personal Health Information Protection Act (PHIPA)

14a. How often have you been unable to help your care receiver despite his/her consent to share information with health/mental health professionals?



14b. How often have you been unable to help your care receiver because he/she has NOT provided consent to share information with health/mental health professionals?



- These questions were originally developed for the Child/Youth Mental Health & Addictions Module (MH/A), but Advisory members felt it applied to all caregivers.
- 21.2% of all caregivers encountered problems helping their care receiver, sometimes or more often, versus 20.6% for the MH/A group, due to professionals not sharing information, despite permission.
- 20.9% of all caregivers encountered problems helping their care receiver sometimes or more often, in cases where the care receiver had not given permission to share information. This was slightly less for the MH/A group (18.9%).

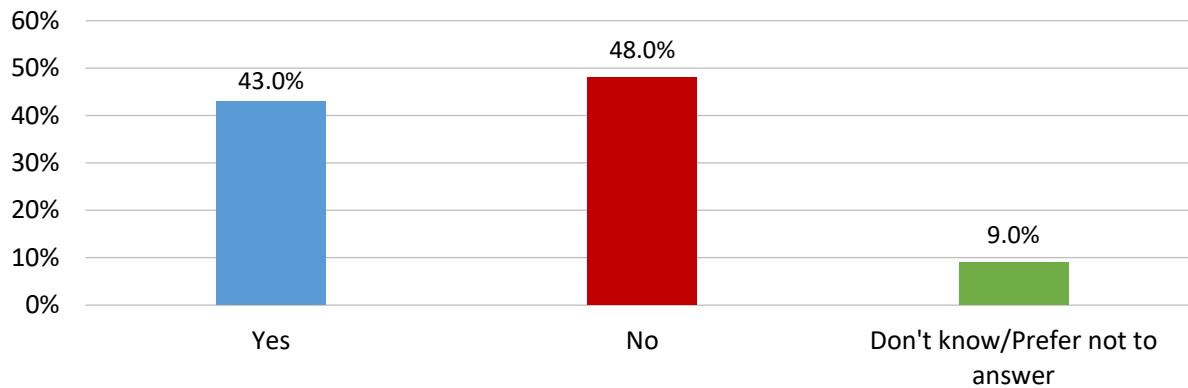
Personal Health Information Protection Act (PHIPA) governs the collection, use and disclosure of personal health information in Ontario.

Key Finding:

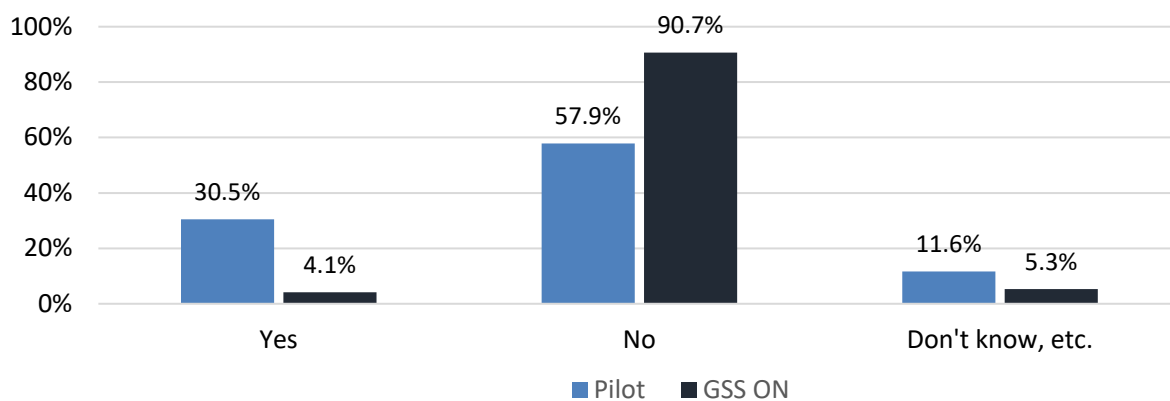
Results were analyzed for our subset of MH/A caregivers to determine if PHIPA would be of greater importance to this group; results suggest little difference across caregivers.

Exhibit 15: Financial Hardship

15a: Experienced Financial Hardship Because of Caregiving?

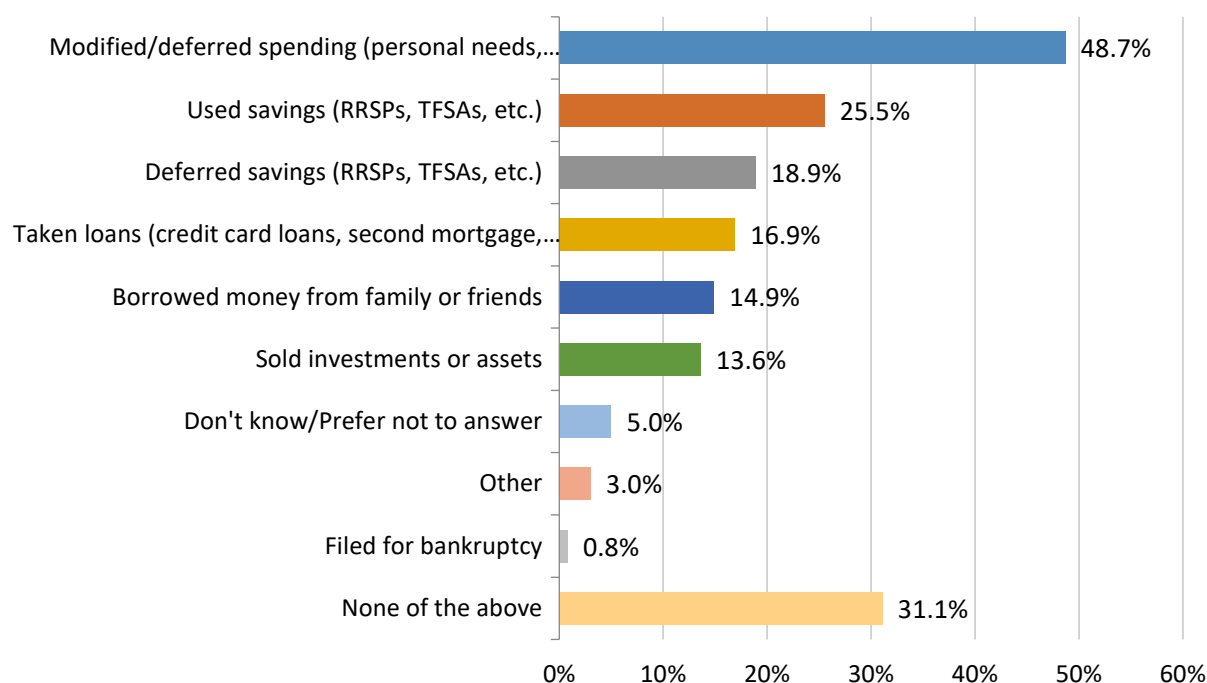


15b: Received Federal Tax Credits?



- 43.0% of pilot caregivers have experienced financial hardship because of their caregiving responsibilities.
- 30.5% of pilot respondents reported receiving caregiver-related Federal tax credits, compared to 4.1% of the GSS-ON group.
- Reasons for not receiving tax credits included not knowing about them, not applying, or a denial of application.
- Estimated non-reimbursed out-of-pocket expenses (graph not shown):
 - \$5,000 to over \$50,000 20.6%
 - \$1,000 to less than \$5,000 33.1%
 - less than \$1,000 26.5%

Exhibit 16: Strategies to Offset Financial Hardship



- More than two-thirds of respondents indicated that they had used one or more strategies to offset the financial hardships associated with caregiving.
- The most common strategy used was to modify or defer spending (48.7%) on things such as personal needs, vacations, etc. The next two most common strategies included using savings (25.5%), or deferring savings (18.9%).

Key Finding:

Caregivers experienced financial hardship because of their caregiving responsibilities. These results raise a concern that as this group of caregivers gets older (with 24.2% already aged 65 or older), they may encounter financial problems as they near retirement.

SECTION E: Qualitative Results

The last section of the survey asked caregivers to respond to a group of open-ended questions. Despite the length of the survey, many caregivers wrote extensively about their experience, including the key messages they would like to give to decision-makers, and the things that had sustained them as caregivers over the years. Below are the overall themes that emerged from this section, and quotations from respondents.

What are the three most important messages, either positive or negative, that you would want to tell the Government and service agencies about caregiving? (89% response rate)

Financial toll: *This is extremely taxing on our family. We have incurred debt, struggled in our marriage and tried to keep our family together. I have not been able to work outside of the home for years. I tried to last year but had to quit. We receive no respite or financial aid.*

Emotional/physical toll: *I'm not coping well; I cry as I type this. Perhaps when CCAC comes into the home to assess the person requiring care, they could follow up with the caregiver to see how they are coping. Take care of the caregiver because when the caregiver breaks down, the whole system breaks down.*

Exclusion from care receiver's treatment planning: *[we need]...more responsive health care people who will listen to the concerns of families and not hide behind the privacy legislation.*

Lack of services: *My brother has been residing in hospital since a car accident in 2009 and at that time was placed on the wait lists for housing but they are lifetime waitlists and we were told to never expect his name to come up for housing. We wish to be a part of our community again and we wish to contribute and give back to the community where we live.*

Difficulty navigating the system: *Navigation is overwhelming for elderly who are unaware of many services (often more economical options) and not informed/referred by formal services such as CCAC.... Burden on the individual to coordinate care is significant and challenging and as a non-family caregiver, I'm not authorized to provide the required support.*

In the past 12 months, what have been the most important things that have helped you or kept you going as a caregiver? (90% response rate)

Love, hope: *Knowing my husband was vulnerable and needed me. I love him in spite of the fact that he no longer recognizes me.*

Sense of responsibility: *My dedication to humanity. They are human beings. They deserve better care.*

External Support (family, professionals, workplace): *I feel that we have a good support network with friends and others who are both support group members and caregivers.*

Sense of humour, self-care: *A sense of humor. Writing. Creating knitted blankets and hooked rugs. Reading. Long walks. Anything that doesn't cost much to "escape" for a few hours, mentally.*

Seeing care receiver do well: *Knowing that it is my child's future that is at stake.*

Conclusions

Pilot Survey Themes

The Family/Friend Caregiver Survey assesses caregiver burden and difficulties, financial and employment impacts, and use (or non-use) of provincial services and supports. Results from our Ontario pilot reveal much vulnerability faced by caregivers, including substantial demands in terms of obligations and roles, along with significant gaps in access to services and supports. Two overall themes emerged as particularly significant for Ontario caregivers:

1. Caregiving Demands & Impacts: Emotional and Financial Factors

The emotional and financial toll on caregivers emerged as a pervasive theme in both the quantitative and qualitative results, with caregivers describing their role as *“exhausting”*, *“crippling”*, and *“emotional, physically, mentally draining”*. At the same time, the results also highlighted the positive aspects of caregiving. Key findings include:

- Emotional support services are needed for **all** caregivers not just those caring for individuals with mental health problems. No or inadequate provincial health insurance coverage for services such as psychotherapy and respite services is a barrier.
- While consent to share information (PHIPA) did not emerge as a significant issue in the quantitative data, qualitative data indicated otherwise, highlighting that for some, exclusion from the care receiver’s treatment plan devalues the caregiver role and its importance.
- Qualitative feedback indicates a lack of respect from health professionals and government regarding caregiver knowledge and contribution to the health care system. In addition, there is a lack of recognition from government regarding the costs associated with caregiving.
- Caregiving has a significant impact on work and/or school responsibilities, suggesting lost productivity, reduced hours, and absenteeism. Qualitative data indicated caregivers are leaving the workforce altogether, or shifting to part-time work.
- Love for the care receiver and a sense of duty are sustaining influences on caregivers. Positive life changes resulting from caregiving, such as improved relationships with family may offer a strength-based approach toward caregiver support.

2. Caregiving Resources & Supports: System Access & Navigation Barriers

Caregivers encounter significant barriers related to service access and system navigation. Key issues include:

- Reluctance from the care receiver to accept/allow services
- Stigma remains a problem for mental health services
- System navigation services are confusing and difficult to access
- Lack of mental health services and/or culturally inappropriate services
- Long wait lists for long-term care beds
- Inadequate training of professionals
- Lack of services for rural residents

Moving Forward

Feasibility, Validity, and Role of the Family/Friend Caregiver Survey

Pilot results demonstrate that the Family/Friend Caregiver Survey can collect meaningful information in an acceptable and accessible manner. The three rounds of cognitive testing have established validity of the survey to capture the caregiving experience in Ontario. As well, online testing has established feasibility, with respondents indicating a willingness to fill out a similar survey in the future for a longitudinal analysis of the caregiving experience in Ontario.

This tool offers support for evidence-based policy planning, decision-making and system monitoring for different audiences. At the provincial government level, the survey can monitor the availability of services

to support strategic objectives (e.g., maintaining individuals in their homes as long as possible); where policies are under consideration or newly implemented (e.g., family care leave), survey data can contribute information about their use and impact. At the community organization level, data can help determine specific gaps and problems in accessing services experienced by caregivers and provide a baseline for monitoring improvement efforts. In addition, the Family/Friend Caregiver Survey has the capability to identify caregiver subgroups that may have unique service needs. For example, younger caregivers who may be balancing education, family and career; those in mid-life managing work responsibilities with the needs of an ill child and/or aging parents; or older caregivers who may be dealing with their own frailties along with caregiving demands.

Next steps include using pilot results to finalize the survey and, in conjunction with our Knowledge User Advisory, to identify opportunities to share our findings and encourage uptake and sustainability.

The Service System

We presented pilot results to a number of external stakeholder groups at the local, provincial, and federal levels. They indicated that our findings were consistent with their experience, and based on their feedback, we identified two strategies for moving forward with caregiver policy and planning in Ontario, and Canada more broadly:

1. Increase Caregiver/Care Receiver Literacy

- Increase public awareness of the high percentage of Ontarians who are likely to become caregivers or to need caregiving.
- Teach basic caregiving skills to everyone.
- Educate the public on available services and supports for caregivers.
- Increase anti-stigma programs related to caregiving and mental health services.
- Provide financial planning and support services for caregivers, with a focus on savings and retirement strategies.
- Improve awareness of and access to caregiver tax benefits.
- Engage with employers to improve workplace responsiveness to employees who are caregivers.

2. Improve System Readiness and Response

- Expand the 'unit of care' to include the caregiver/care receiver dyad.
- Review and educate providers across the system regarding when privacy concerns and information sharing issues do and do not require exclusion of the caregiver as part of the circle of care.
- Make navigational services transparent and user-friendly.
- Investigate and implement strategies to increase care recipient acceptance of available services and supports.
- Provide tiered and flexible support for different levels and types of caregiver/care recipient needs.

This report and additional information regarding the Family/Friend Caregiver Project is available at www.hsprn.ca

References

- Bakas, T., Austin, J.K., Jessup, S.L., Williams, L.S., & Oberst, M.T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal of Neuroscience Nursing*. 36(2), 95-106.
- Bakas T, Champion V, Perkins SM, Farran CJ, Williams LS. (2006). Psychometric testing of the revised 15-item Bakas Caregiving Outcomes Scale. *Nursing Research*. 55(5):346-355.
- Carlson, D.S. and Frone, M.R. (2003). Relation of behavioral and psychological involvement to a new four-factor conceptualization of work-family interference. *Journal of Business and Psychology*. 17(4):515.
- Hollander, M.J., Liu, G., and Chappell, N.L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*. 12(2): 42-49.
- Statistics Canada. (2012). General Social Survey on Caregiving and Care Receiving, Cycle 26. Available at http://www23.statcan.gc.ca/imdb-bmdi/instrument/4502_Q2_V3-eng.pdf, retrieved October 7, 2013.
- Sinha, M. (2013). Spotlight on Canadians: Results from the General Social Survey: Portrait of Caregivers. Statistics Canada. Available at <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf>, retrieved November 5, 2013.

Appendix A: Survey Framework

Framework					
DOMAIN	Caregiving Work Demands	Caregiving Work Impact	Caregiving Resources/ Supports	Attitude/ Culture	Caregiving Uncertainties
CONSTRUCTS	<ul style="list-style-type: none"> • Type • Time • Difficulty 	<ul style="list-style-type: none"> • On Work • On Family • On Self 	<ul style="list-style-type: none"> • Social network • Publicly-funded • Barriers 	<ul style="list-style-type: none"> • Socio-cultural beliefs 	<ul style="list-style-type: none"> • Current • Anticipated
Coverage (level of detail)					
BROAD OVERVIEW (all caregivers)	Core Survey				
MEDIUM DEPTH (all caregivers)	<ul style="list-style-type: none"> • Difficult behaviours (Core Survey) 	<ul style="list-style-type: none"> • Impact on work (Core Survey) 	<ul style="list-style-type: none"> • Publically provided services (Core Survey) 		
IN-DEPTH (specific groups of caregivers)	Specialized Modules				

Appendix B: Revisions to Version 1 (dated November 15, 2016)

OVERVIEW:

The revisions in this version (Version 2) of the report stem from two main sources: miscalculations in the first set of analyses (specifically, using the wrong denominator) and, in a few cases where both a primary and secondary form of a question were asked, only reporting the results from the primary question.

The impact of these changes is that some percentages and the corresponding text have been modified (see list below). However, none of the overall patterns or Conclusions have been affected.

LIST OF REVISIONS (specific changes are highlighted):

RESULTS (Summary, paragraph 3):

The number one service used by care receivers was “health and other therapies” (76.2%), with “recreation/social support” (30.1%) and “system navigation” (24.5%) identified by caregivers as the most needed but unused services.

Exhibit 6b: Tasks with Most and Least Difficulty

Extremely/Very Difficult (%)		Not Difficult (%)	
Arrange care while away	49.2	Medical treatments	48.1
Managing behaviour	42.9	Tasks outside home (e.g. shopping)	36.8
Emotional support	36.4	Household tasks (e.g., laundry)	29.6
Communication	30.8	Planning activities for care receiver	25.3
Seek/give information	27.8	Assist w/ walking, etc.	25.0
Monitoring symptoms	25.7		

- 68.5% of our caregivers identified emotional support or “being there” as a task that required a great amount of time. Monitoring symptoms (44.0%) and transportation (44.0%) were the next two most time consuming tasks identified.
- The tasks with the highest rating in terms of difficulty were arranging care while the caregiver was away at 49.2% and managing behaviour at 42.9%.
- 48.1% of respondents did not find medical or nursing treatments difficult to perform. This suggests that this sample of caregivers have a reasonable partnership with the formal health care system and/or are not caring for people with medically complex problems.

Exhibit 11: Caregiver Service Non-use and Barriers

Service	Education/ Support (%)	MH Services (%)	Respite (%)
Needed but not used	20.2	15.6	28.5
Barriers to Service Use			
Hard to access	49.2	31.3	32.6
Financial issues	19.7	35.4	37.2
Unable to/felt guilty leaving care receiver	9.8	14.6	31.4
System confusing	32.8	18.8	20.9
Afraid (stigma)	8.2	18.8	3.5
Services inappropriate	19.7	12.5	20.9

- **Respite** was the most needed but not used service (28.5%):
- Main barriers were financial issues, difficulty accessing services, and feeling unable to or guilty about leaving the care receiver.
- **Education/Support** services were needed but not used by 20.2% of caregivers:
- Barriers included difficulty accessing services (49.2%), financial issues (19.7%) and inappropriate services (19.7%).
- **Mental health** services were identified by 15.6% of caregivers as needed but unused:
- Barriers included financial (35.4%) and access (31.3%) issues.
- “Fear of what people would think” was selected by 18.8% of respondents as a barrier to mental health services, indicating a sense of stigma related to these services.

Exhibit 12: Care Receiver Service Use and Met Need

Service	Health & Other Therapies (%)	Home- based (%)	System Nav. (%)	Recreation/ Soc.Support (%)	Long- term Care (%)
Used	76.2	38.1	31.8	33.8	17.2
Extent of Met Need					
A great deal	22.2	31.3	31.3	23.5	26.9
Fair amount	30.0	31.3	19.8	30.4	40.4
Somewhat	34.3	33.0	40.6	44.1	26.9
Not at all	8.3	4.3	6.3	2.0	5.8

- The number one service used by care receivers was health and other therapies at 76.2%, followed by home-based services (38.1%) and recreation/social support (33.8%).
- As with caregiver services, when asked to rate the extent to which a service met care receiver needs, “somewhat” was selected most frequently across four services, indicating room for improvement. The exception was long-term care where the most frequent rating was “fair amount.”

Exhibit 13

Service	Health & Other Therapies (%)	Home-based (%)	System Nav. (%)	Recreation/ Soc.Support (%)	Long-term Care (%)
Needed but not used	6.3	14.6	24.5	30.1	13.9
Barriers to service use					
Care receiver reluctant to use	*	43.2	31.1	67.0	45.2
Hard to access	*	38.6	40.5	34.1	50.0
System confusing	*	20.5	40.5	13.2	11.9
Financial issues	*	31.8	17.6	26.4	26.2
Poor quality	*	15.9	14.9	14.3	9.5
Guilty using service	*	9.1	0.0	3.2	11.9
Afraid (stigma)	*	0.0	2.7	2.2	4.8

- **Recreation and social support** were the services that were most needed but not used at 30.1%. The primary barrier was the care receiver’s reluctance to use those services (67%).
- **System navigation** was the second most needed but not used service at 24.5%:
- Main barriers included a system that was hard to access (40.5%) and confusing (40.5%).
- Navigation services, designed to help caregivers navigate a confusing system, are confusing and inaccessible in and of themselves.
- **Home-based services** was selected next as a needed but not used service (14.6%):
- Care receiver reluctance was the most selected barrier at 43.2%, followed by hard to access (38.6%).
- **Long-term care** was selected by 13.9% as a needed but not used service:
 - Hard to access (50.0%) and care receiver reluctance (45.2%) were the top two barriers.