BUILDING A FRAMEWORK FOR SUPPORTING MEANINGFUL FAMILY CAREGIVER ENGAGEMENT:

SURVEY FINDINGS AND RESEARCH PROCESS

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Royal

Mental Health - Care & Research
Santé mentale - Soins et recherche

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ACKNOWLEDGEMENTS

We acknowledge and thank family caregivers, staff, and leaders connected to participating Ontario hospitals and community mental health services who were part of the collaborative team that developed the surveys, as well as those who shared their experiences and ideas that provided the basis for this report.

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SUMMARY

WHY ARE WE INTERESTED IN THIS RESEARCH?

> " This project is in support of the significant contributions made by caregivers who volunteer their time and energy toward quality improvement efforts and have an expectation of return on their investment. "
>
> - Cynthia Clark

Health care is moving towards a model of governance which includes patients and their family members as collaborative partners in all aspects of standard care, as seen with the *'The Excellent Care for All Act'*[1] and the novel standard of governance structure engagement required by Ontario Health Teams[2]. This change has resulted in an increased demand for volunteer family advisors and the development of resources that aid in the adoption and use of new engagement frameworks to meet these requirements.

Until recently, a significant amount of research and resources on caregiver engagement in the health care system has paid little attention to the unique and complex experiences of family caregivers in the area of mental health and substance use and concurrent disorders. The goal of this research is to acquire a better understanding of how to build and maintain meaningful collaborative partnerships within the context of mental health, substance use and concurrent disorders, and to use this understanding to create knowledge products that will benefit mental health organizations across Ontario.

1. *Excellent Care for All Act*. Ottawa, ON: Government of Ontario; 2010.
   https://www.ontario.ca/laws/statute/10e14?_ga=2.76494229.1892961893.1598840951-250598173.1598840951.

2. Ontario HT. *Ontario Health Teams: Guidance for Health Care Providers and Organizations*.; 2019.
   http://health.gov.on.ca/en/pro/programs/connectedcare/oht/docs/guidance_doc_en.pdf.
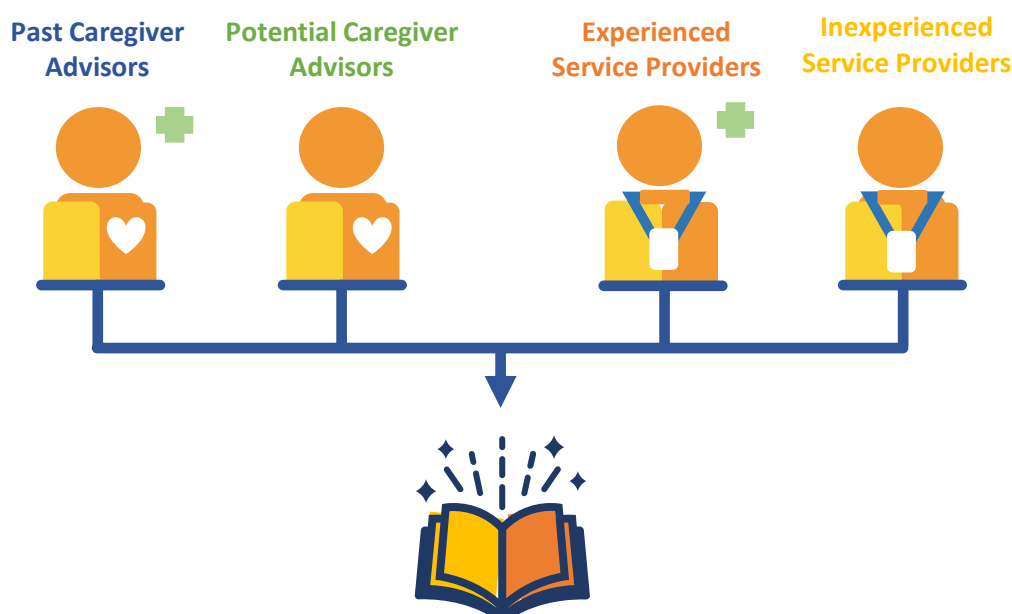
The Canadian Institute for Health Research (CIHR) funded this project under the Strategy for Patient-Oriented Research (SPOR). In a nutshell, this strategy:

- Engages patients*, researchers, and other stakeholders as partners in research
- Answers questions that are important to patients
- Aims to improve health and the health care systems

As in keeping with the SPOR Grant objectives[3], we engaged caregivers and service providers, as our target populations, throughout the research project.

For example, from its creation, this project has been directed and initiated by caregiver advisors at The Royal based upon their collective experiences of over 12 years on the Family Advisory Council. By including collaboration from the very first step, our research proposal not only met the criteria for a high level of engagement for SPOR but included a named principal investigator who was a caregiver with lived experience; their experiences and perceptions of meaningful engagement practices were the foundation of this research. Since then, every step of this process has been co-designed by a team of caregiver advisors, service providers, and researchers.

In order to make the research more inclusive, survey participants included both caregivers and service providers associated with mental health hospitals and community settings in Ontario with a variety of different collaborative involvement history.

In this context "patients" include families.

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3. Canadian Institutes of Health Research. Strategy for patient-oriented research: Patient engagement framework. 2014:1-11.
   http://www.cihr-irsc.gc.ca/e/48413.html

By collecting the perspectives from both caregivers and service providers with varied levels of collaboration experience, we strived to provide insights that would guide the creation of tools and strategies meant to facilitate successful and meaningful collaboration in the Ontario mental health and substance use and concurrent disorder system from an organization's identification of need for advisors, through their recruitment, orientation, task assignment, and sustainable commitment. Yet, this was not a simple process. We had to include the input of caregivers and service providers throughout our three phases.

Phase 1: Discovery	Collect the perspectives of **caregivers and service providers,** with or without experience in caregiver advising, about their needs.
Phase 2: Collaboration Event	Discuss the data with **expert caregiver advisors and related service providers** to establish best practices and information delivery options.
Phase 3: Create Knowledge Products	Create knowledge products with caregiver advisors and service providers, aimed at mental health services in the community organizations and institutions.

This report covers findings from phases one and two of the project. At the time of its publication, phase three – the phase to produce knowledge products – was underway. It is expected that these knowledge products will be publicly available by September 2021.

- Many past caregiver advisors were directly recruited by existing caregiver advisors and service providers.

- *Being able to see beyond their personal experience* and *respectful* were considered important qualities for caregiver advisors by caregivers and service providers.

- A majority of caregivers and service providers wanted their involvement with caregiver advising to result in improved experiences for caregivers and clients. Those experienced with collaboration wished to also impact policy.

- A majority of caregivers wanted to be heard and respected while a majority of service providers wanted to gain knowledge on the caregiver lived experience.

- More potential caregiver advisors were prevented from engagement by career, volunteering and work demands, and family-related duties than past caregiver advisors.

- Approximately one fourth of all caregivers were hindered or prevented from engagement by the stigma related to their loved one's condition.

- Providing an orientation for caregiver advisors was considered important by a majority of participants, although approximately half of past caregiver advisors reported having received an orientation.

- Several training topics were considered important for caregiver advisors by a majority of participants with past collaboration experience, although a majority past caregiver advisors did not receive formal training on any of these subjects.

- Of the training topics suggested, *how to design and conduct research* and *fundraising strategies* were considered important by the least number of past advisors and experienced service providers.

- Past caregiver advisors reported that training should be specific to the position of the advisors to avoid unnecessary training.

- While a majority of service providers reported that caregiver engagement skill training was important, only approximately one fourth of experienced service providers said they had received comprehensive engagement skill training.

- Creating a welcoming and accommodating environment for caregiver advising and being given opportunities to be matched with suitable and interesting tasks was deemed important by all respondents.

- A majority of participants with collaboration experience reported that upper management supported and enabled working with caregiver advisors.

- More than half of past caregiver advisors felt they were recognized as an equal contributor.

METHODOLOGY

TEAM STRUCTURE

A caregiver advisor acted as the principal investigator and visionary of the project. A research coordinator was hired to work directly under the principal investigator to manage the project and research efforts. Two caregiver advisors with previous research experience consulted on the project based upon their expertise and connections. Additional support was gained from a team of researchers, service providers, and caregivers from local hospitals and community organizations who acted as consultants throughout the process. Additional external service providers and caregiver advisors were invited to consult during specific phases of the project to ensure the team had represented the needs of the target populations. All caregivers involved were compensated for their time accordingly.

TARGET POPULATION

To collect the different perspective of those involved with collaboration, the four targeted populations were defined as such:

1 For **past caregiver advisors**, the participant must have been a caregiver – such as a family member or close friend who assists a person living with a mental illness or substance use and concurrent disorder – who has been involved formally with a hospital, community organization, or government agency to inform on all levels of the organization's operations in a variety of positions, such as working groups or steering committees.

2 For **potential caregiver advisors**, the participant must have been a caregiver who has **not** been involved formally with a hospital, community organization, or government agency to inform on all levels of the organization's operations in a variety of positions.

3 For **experienced service providers**, the participant must have been a staff member at an organization that provides mental health and/or substance use services within Ontario, Canada, and have experience working with caregiver advisors at their organization to inform on all levels of the organization's operations in a variety of positions.

4 For **inexperienced service providers**, the participant must have been a staff member at an organization that provides mental health and/or substance use services within Ontario, Canada, and have **no** experience working with caregiver advisors at their organization to inform on all levels of the organization's operations in a variety of positions.

PHASE ONE: DISCOVERY

SURVEY DEVEOLPMENT

Survey questions on the original templates were created from gaps and recurring topics found in an environmental scan conducted by two researchers – one who also identified as a caregiver advisor – on currently available products for family caregiver advisor engagement in Canada. To focus our survey development, the questions were carefully selected and framed in a way that would best measure the perceived gaps in engagement practices; highlight the lived experiences of all parties involved in engagement; capture a snapshot of the environmental factors that support or hinder meaningful partnerships; and provide an opportunity for possible future players to share their understanding and vision of engagement.

With collaboration in mind, three teams were created: one team was populated with caregiver advisors, the second team included service providers, and the third team consisted of researchers. The first team co-authored and reviewed the surveys for caregivers. The caregiver surveys then acted as a comparable base for the service provider surveys, which were co-authored and reviewed by the team of service providers. The team of researchers reviewed all surveys to ensure that the questions were clear and mechanically valid.

Once our teams were content with the survey drafts, an external team of caregiver advisors were asked to review the caregiver surveys and an external team of service providers reviewed the service provider surveys. Their comments and corrections were adapted into the final surveys. In the end, we produced four surveys. While questions were specific to the target demographic of each survey, certain questions were repeated on all surveys. The involved caregiver advisors were compensated for their time.

SURVEY CIRCULATION

Surveys were hosted on Qualtrics from October 16th, 2020 to November 30th, 2020 and accessed through four, anonymous, separate links. We circulated the surveys through personal networks of the principal investigator and team members by email invitations approved by The Royal's Research Ethics Board (REB). The Royal advertised the survey with its staff members and had the study available on the website in English. Using an REB approved poster, we advertised on EENET through their newsletter and Online Forum. We also paid for a short Facebook advertisement.

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SAMPLE

SAMPLE DISTRIBUTION

To be included in the sample, participants had to be at least 16 years old, be able to access the online survey (English), and reside in Ontario, Canada, at the time of the survey. No limitations were set on how long ago the experience as a caregiver advisor or service provider occurred.

More information on participants can be found in **Appendix B**.

Number of Participants (N=122)

Past Caregiver Advisors	Potential Caregiver Advisors	Experienced Service	Inexperienced Service
40	44	24	14
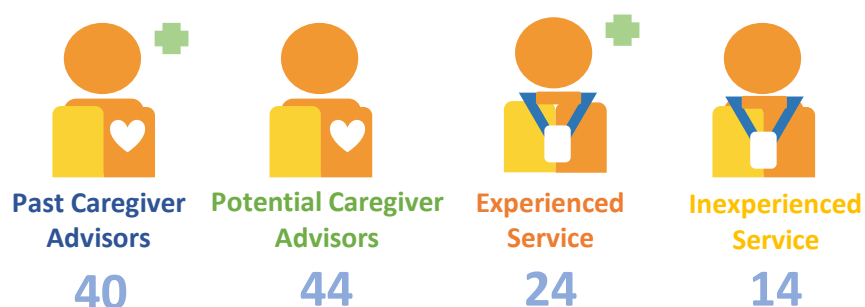
Figure 1. Sample Composition

- Inexperienced Service Providers — 11%
- Experienced Service Providers — 20%
- Past Caregiver Advisors — 33%
- Potential Caregiver Advisors — 36%

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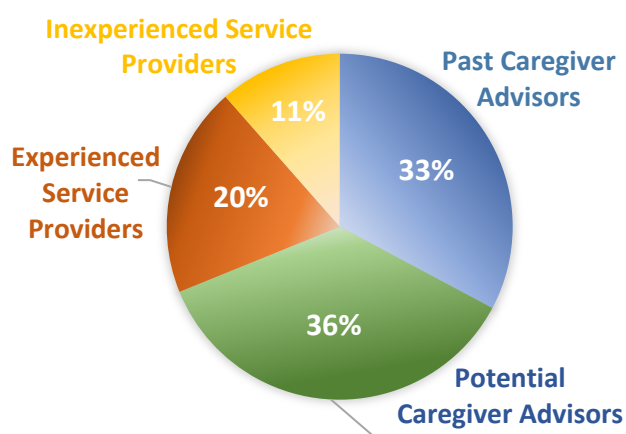
Results

RECRUITMENT

Recruitment can be a difficult task for any council or committee. There are a number of considerations that need to be explored in order to create a successful team and use resources effectively. We've broken down the survey answers that were gathered surrounding recruitment into specific topics to inform mental health organizations attempting to begin recruitment:

1. How to recruit caregiver advisors?

2. What to look for in a caregiver advisor?

3. Why caregivers and service providers get involved?

4. What prevents caregivers from getting involved?

When we asked past caregiver advisors how they originally heard about the advisor position, many reported being directly recruited by an existing caregiver advisor or staff (Figure 2). Formal types of advertising, such as advertising on social media or the local newspaper, were less commonly experienced by caregivers who successfully became involved as advisors. Examples of *other methods* included: hearing of the position from a support group or by personally reaching out to an organization to become more involved.

For potential caregiver advisors, however, a majority recommended using social media or the organization's website to advertise the advisor position. Direct recruiting from existing caregiver advisors and staff was still recommended. Other suggestions from potential caregiver advisors included using specific social media platforms, such as LinkedIn, e-mail invitations, or physical posters within the organization.

Figure 2. Percent of past caregiver advisors who were recruited via these methods (left) and percent of potential caregiver who suggest using the following recruit (right).

PAST CAREGIVER ADVISORS WERE RECRUITED BY...

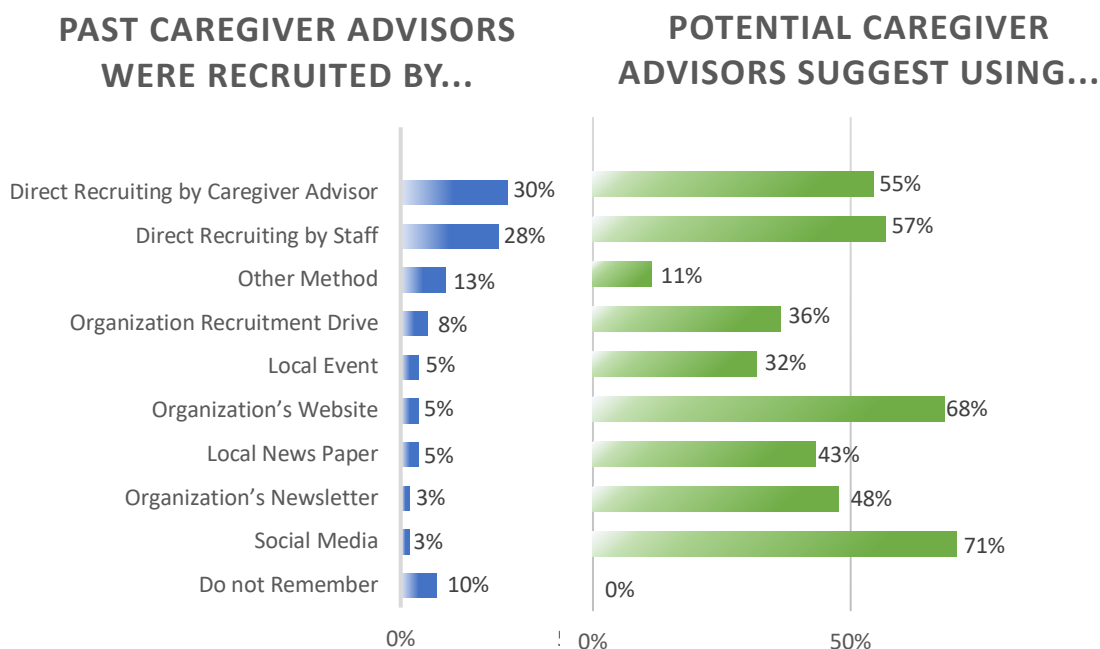| Method	Percent
Direct Recruiting by Caregiver Advisor	30%
Direct Recruiting by Staff	28%
Other Method	13%
Organization Recruitment Drive	8%
Local Event	5%
Organization's Website	5%
Local News Paper	5%
Organization's Newsletter	3%
Social Media	3%
Do not Remember	10%

POTENTIAL CAREGIVER ADVISORS SUGGEST USING...

Method	Percent
Direct Recruiting by Caregiver Advisor	55%
Direct Recruiting by Staff	57%
Other Method	11%
Organization Recruitment Drive	36%
Local Event	32%
Organization's Website	68%
Local News Paper	43%
Organization's Newsletter	48%
Social Media	71%
Do not Remember	0%

Service providers who had experience working with caregiver advisors reported that their organization often recruited caregiver advisors through direct recruitment by existing caregiver advisors, staff, and from the organization website (Figure 3). Other methods reported by service providers with experience include advertising through family councils, sharing among caregiver distribution lists, and word of mouth.

Service providers who had not worked with caregiver advisors previously largely did not know what advertising methods were used to recruit caregiver advisors, however some were aware of advertising on the organization's website and direct recruiting by staff.

Figure 3. Percent of service providers who felt their organizations used to following caregiver recruitment methods.

ORGANIZATION OF EXPERIENCED SERVICE PROVIDERS USE...

Method	Percent
Direct Recruiting by Caregiver Advisor	38%
Direct Recruiting by Staff	54%
Other Method	13%
Organization Recruitment Drive	13%
Local Event	0%
Organization's Website	46%
Local News Paper	0%
Organization's Newsletter	21%
Social Media	29%
No Active Recruitment	13%
Do Not Know	21%

ORGANIZATION OF INEXPERIENCED SERVICE PROVIDERS USE...

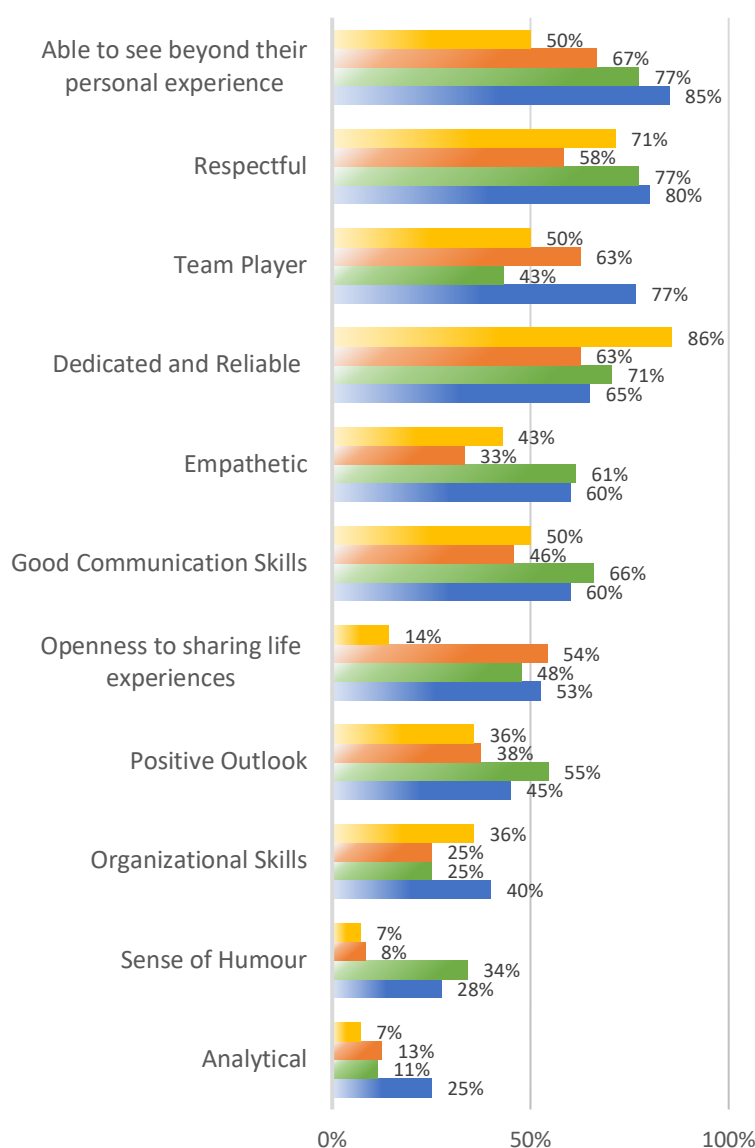| Method	Percent
Direct Recruiting by Caregiver Advisor	0%
Direct Recruiting by Staff	29%
Other Method	7%
Organization Recruitment Drive	14%
Local Event	7%
Organization's Website	36%
Local News Paper	0%
Organization's Newsletter	7%
Social Media	14%
No Active Recruitment	7%
Do Not Know	57%

Despite the relative common prevalence of advertising on the organization's website reported by service providers, most past caregiver advisors did not hear about the position by the organization's website. Based upon the methods suggested by potential caregiver advisors, more focus may need to be placed on advertising through social media to reach new caregiver advisors.

Figure 4. Percent of participants who felt these qualities were very important for caregiver advisors.

- Inexperienced. Service Provider
- Experienced Service Provider
- Potential Caregiver Advisor
- Past Caregiver Advisor

Able to see beyond their personal experience
- 50%
- 67%
- 77%
- 85%

Respectful
- 71%
- 58%
- 77%
- 80%

Team Player
- 50%
- 63%
- 43%
- 77%

Dedicated and Reliable
- 86%
- 63%
- 71%
- 65%

Empathetic
- 43%
- 33%
- 61%
- 60%

Good Communication Skills
- 50%
- 46%
- 66%
- 60%

Openness to sharing life experiences
- 14%
- 54%
- 48%
- 53%

Positive Outlook
- 36%
- 38%
- 55%
- 45%

Organizational Skills
- 36%
- 25%
- 25%
- 40%

Sense of Humour
- 7%
- 8%
- 34%
- 28%

Analytical
- 7%
- 13%
- 11%
- 25%

0%   50%   100%

When we asked participants which qualities or characteristics were important for a caregiver advisor, many agreed that the ability to see beyond their personal experience was very important, as was being respectful (Figure 4). Other important qualities mentioned commonly included active listening, a willingness to learn, availability, professionalism, patience, open mindedness, being non-judgmental, organization knowledge, and previous experience.

In most of the qualities, caregivers largely agreed on which qualities were very important regardless of their experience.

Compared to caregivers and service providers with experience, more service providers who did not have any experience working with caregiver adivsors considered dedication and reliability very important while less considered 'openness to sharing life experiences' very important. These differences may highlight perception differences between those who have had experiences either as a caregiver or working with them, and those who have not.

Most participants, no matter their demographic category, wanted their involvement to 'improve the experience of caregivers and clients' (Figure 5). A majority of those with experience as caregiver advisors, or as service providers working with caregiver advisors, wanted their involvement to impact policy and have the opportunity to work with clients, family, and staff.

Figure 5. Percent of participants who felt the following impacts of their involvement were important.

Legend:
- Past Caregiver Advisors
- Potential Advisor Caregivers
- Experienced Service Provider
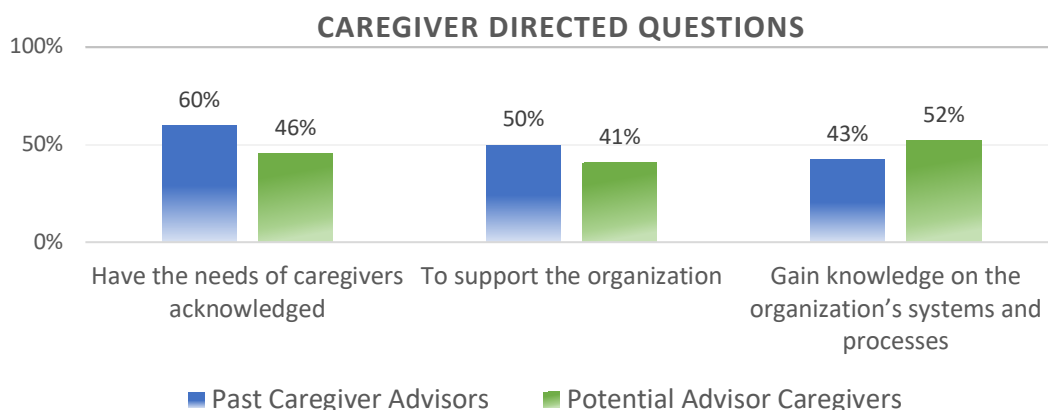- Inexperienced Service Provider
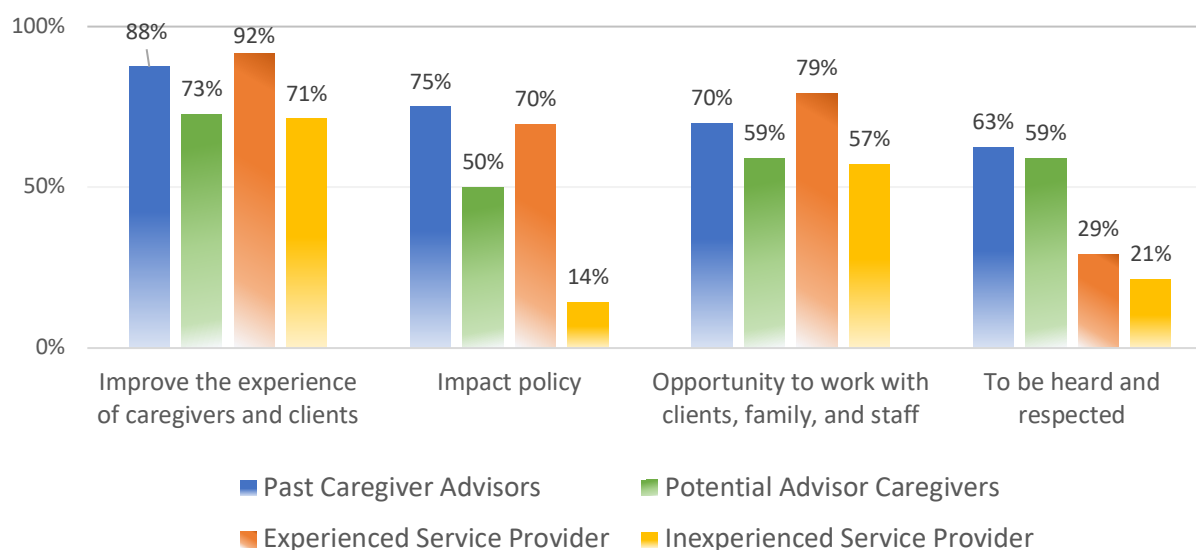
WHAT DO THEY WANT?

When asked what else they wanted from the experience, many respondents reported that they wanted to **create change**, demonstrating that the focus for involvement was centered on the practical results from their work. Service providers also wanted their involvement to result in caregivers receiving more recognition.
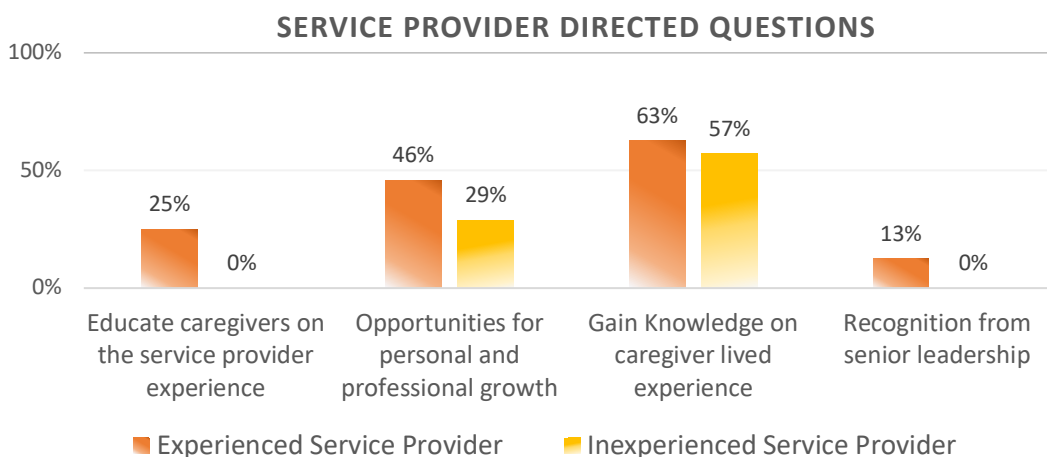
Of the caregiver directed questions, approximately half wanted their involvement to give acknowledgement to the needs of caregivers (Figure 6). Reflecting on Figure 5, more caregivers wanted to improve the experience than have their needs acknowledged, demonstrating that more caregivers valued creating practical change for themselves and their loved one beyond simply receiving recognition for their needs.

Figure 6. Percent of caregivers who felt the following impacts of their involvement were important.

CAREGIVER DIRECTED QUESTIONS

	Have the needs of caregivers acknowledged	To support the organization	Gain knowledge on the organization's systems and processes
Past Caregiver Advisors	60%	50%	43%
Potential Advisor Caregivers	46%	41%	52%

Of the questions directed to service providers, very few wanted their involvement to result in recognition by senior leadership, although approximately half had an interest in gaining knowledge on the caregiver lived experience (Figure 7). Some saw it as an opportunity for personal and professional growth.

Figure 7. Percent of service providers who felt the following impacts of their involvement were important.

SERVICE PROVIDER DIRECTED QUESTIONS

	Educate caregivers on the service provider experience	Opportunities for personal and professional growth	Gain Knowledge on caregiver lived experience	Recognition from senior leadership
Experienced Service Provider	25%	46%	63%	13%
Inexperienced Service Provider	0%	29%	57%	0%

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When caregivers were asked what had prevented or hindered their engagement in the past, most commonly reported previous career, volunteering, work, and family-related duties and interpersonal demands, prevented or hindered their engagement (Figure 8). This was especially true for a majority of potential caregiver advisors who were prevented by their family-related duties and interpersonal demands. For all items mentioned, more potential caregiver advisors reported being hindered.

Language and cultural barriers were reported least often as preventing or hindering engagement; however, as the survey was only administered in English, the sample may not have included participants who would find this barrier more problematic.

Figure 8. Percent of caregivers who were prevented or hindered from engagement by the following items.

Career, volunteering, or work demands: 68% / 50%
Family-Related Duties and Interpersonal demands: 89% / 45%
Stigma related to loved one's condition: 25% / 23%
Financial limitations: 25% / 23%
Prior trauma with mental healthcare/hospital system: 21% / 15%
Personal mental health: 27% / 13%
Personal physical health: 30% / 13%
Language or cultural barriers: 2% / 3%

■ Prevented Potential Caregiver Advisors from Engaging   ■ Hindered Past Caregiver Advisors

WHAT ELSE HINDERED THEM?

When we asked past caregiver advisors what else had hindered their engagement in the past, many reported a lack of support from organization they advised in, lack of resources, and specifically referred to 'red tape' that prevented change. They also experienced tokenism and felt that they were not heard or respected.

When we asked potential caregiver advisors what other factors had prevented their engagement in the past, the most commonly reported limitations were a lack of awareness of the available positions and a general lack of availability. A renewed focus on increasing awareness of available caregiver advisor positions may increase recruitment of new caregiver advisors.
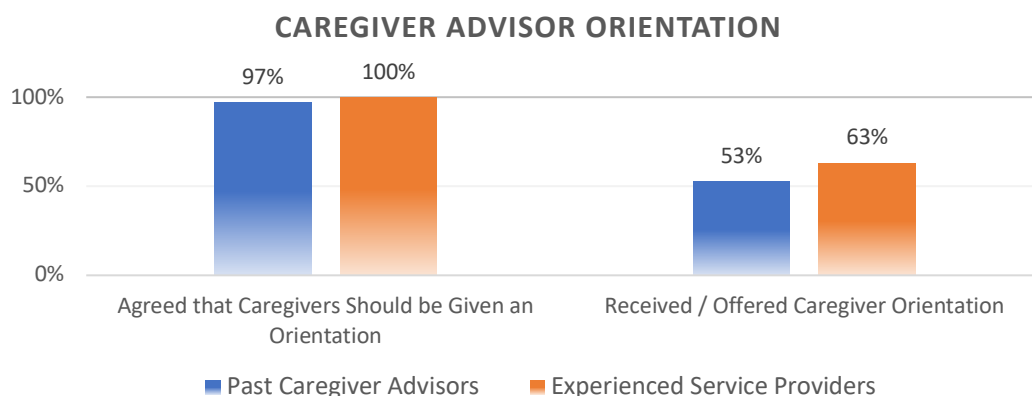
TRAINING

INVESTING IN ADVISING

Once a team has been recruited, there is the daunting task of training the members. From orientation to specific training topics, we have summarized the survey findings to inform mental health organizations on the current need for training:

1. Who needs an orientation?

2. What to teach caregiver advisors?

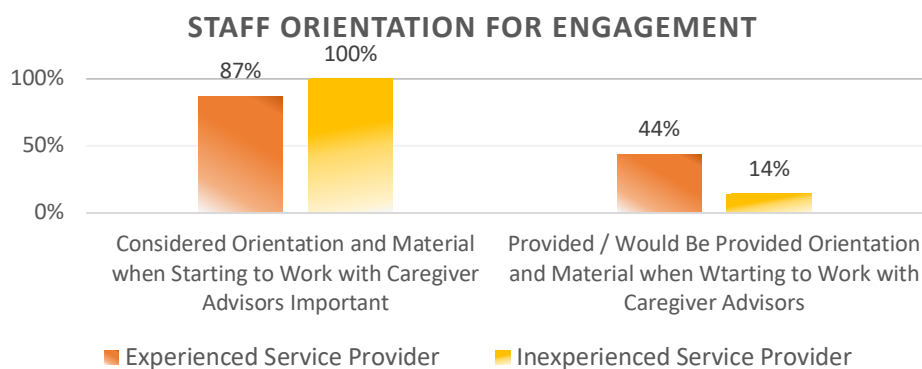3. Do service providers need training?

Past caregiver advisors and experienced service providers both felt that caregiver advisors should receive an orientation for the position; however, approximately half of the past caregiver advisors had received an orientation, and more than half of experienced service providers reported that caregiver advisor orientation was provided by their organization (Figure 9).

Figure 9. Percent of participants on their view or and experience with caregiver advisor orientation

CAREGIVER ADVISOR ORIENTATION

Similarly, a majority of service providers felt that organizations should provide orientation and material package when starting to work with caregiver advisors, although less than half of experienced service providers reported that their organization provided those materials, and a minority of inexperienced service providers felt that their organization would be provided those materials for engagement if they were to get involved (Figure 10). When asked what had hindered their work previously, experienced service providers reported that a lack of training/orientation had hindered their work with caregiver advisors in the past.

Figure 10. Percent of service providers on their view or and experience with orientation

STAFF ORIENTATION FOR ENGAGEMENT

Past caregiver advisors and experienced service providers were asked which topics caregiver advisors should be trained on (Figure 11). A majority felt that caregiver advisors should be trained on the organization's structure. However, only approximately half had either received the training or felt their organization provided the training on an organization's structure. More strikingly, less than 25% of participants felt that their organization provided training on 'how to share their personal experiences', despite that the majority of participants felt that this training was important.

Figure 11. Percent of participants on topics they feel caregiver advisors should be trained on.
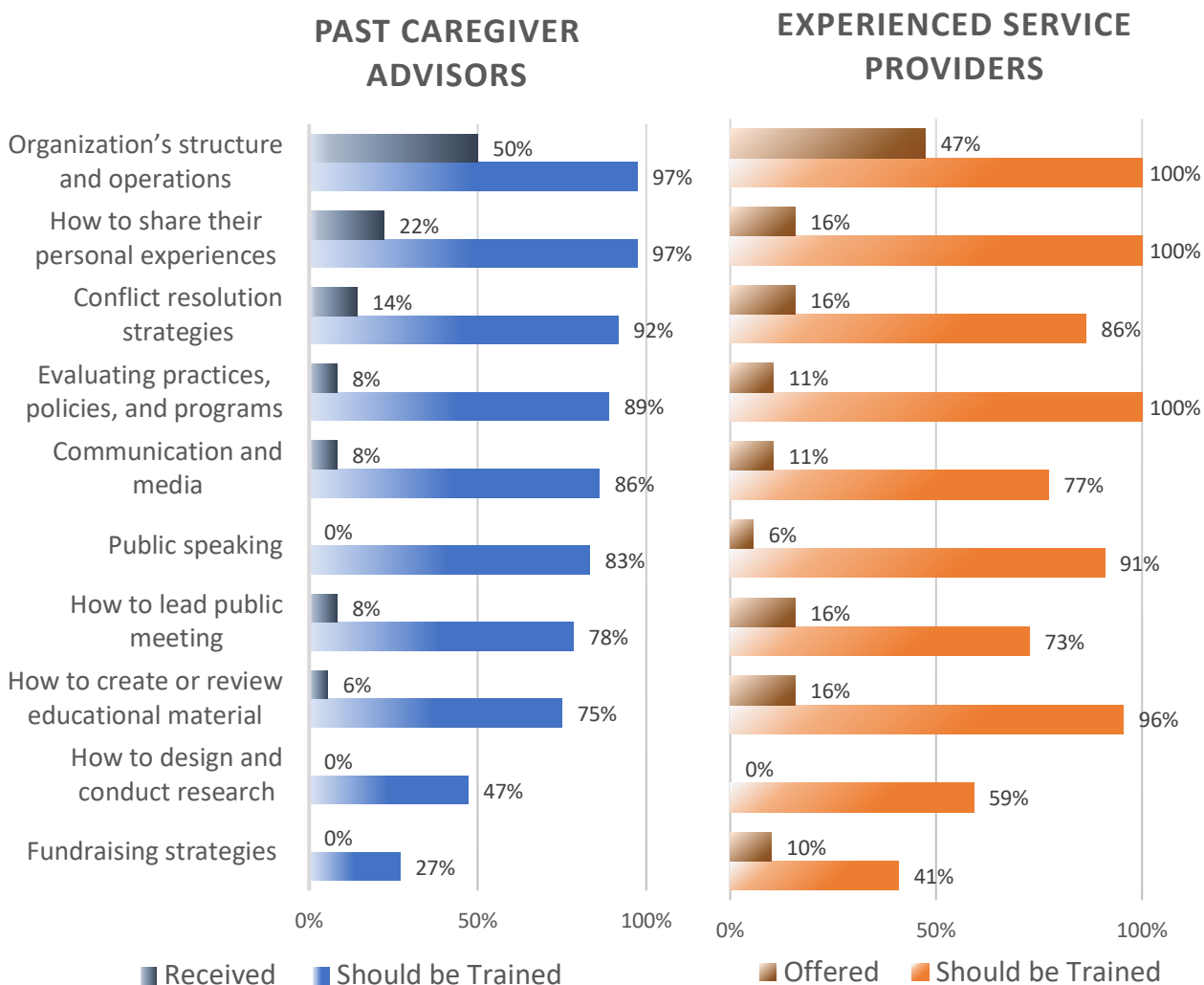
OTHER TRAINING TOPICS?

Other topics suggested by caregivers and service providers included technology training, and mental health training. It was also noted by past caregiver advisors that despite a lack of formal training, they were informally taught on a number of subjects during the course of their experience.
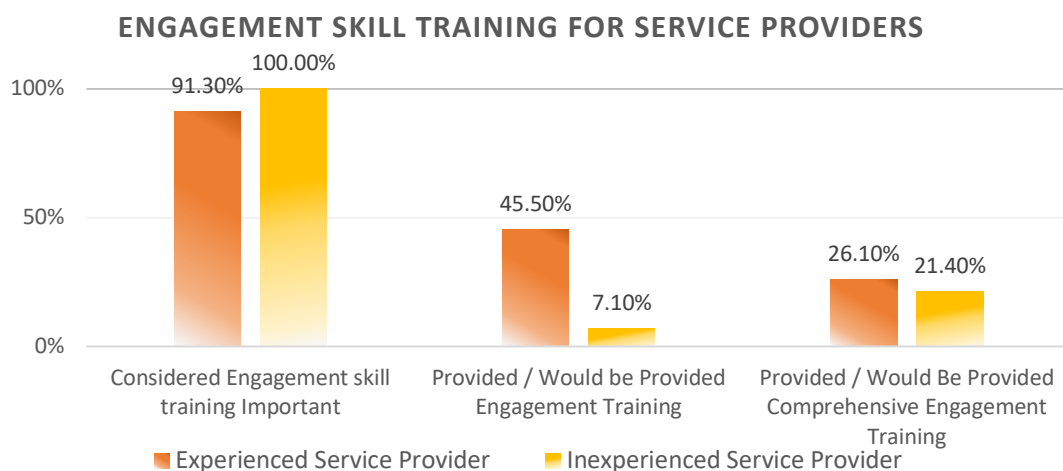
Caregiver advisors, however, felt it was important to note that training should be dependent upon the specific role of the caregiver advisors, meaning that there is no 'one-size-fits-all' when it comes to training caregiver advisors who do not have the additional time to take training unrelated to their position.

A vast majority of service providers considered caregiver engagement skill training important; however, less than half of service providers with experience stated that their organization provided the training, and even less considered their training comprehensive (Figure 12). Very few potential service providers felt that their organization would provide caregiver engagement skill training.

When asked if they were given comprehensive training on how to engage caregiver advisors, approximately one quarter of experienced service providers felt they received the training while approximately 21% of inexperienced service providers felt they would receive that training. These results suggest that there is a lack of current comprehensive engagement skill training for service providers despite the enormous importance on caregiver engagement skill training.

Figure 12. Percent of service providers on engagement skill training for service providers.

ENGAGEMENT SKILL TRAINING FOR SERVICE PROVIDERS

- 91.30% / 100.00% — Considered Engagement skill training Important
- 45.50% / 7.10% — Provided / Would be Provided Engagement Training
- 26.10% / 21.40% — Provided / Would Be Provided Comprehensive Engagement Training

■ Experienced Service Provider   ■ Inexperienced Service Provider

SUSTAINING ENGAGEMENT

Training is only one part of creating a successful team; there are important considerations needed to ensure that the team members remain motivated and involved. To better understand their needs, we have summarized the survey findings to inform mental health organizations on considerations that help sustainability of a team and illustrate the experiences or expectations highlighted by those involved:

1. What do caregiver advisors and service providers consider important for engagement?

2. Current and past experiences of those involved

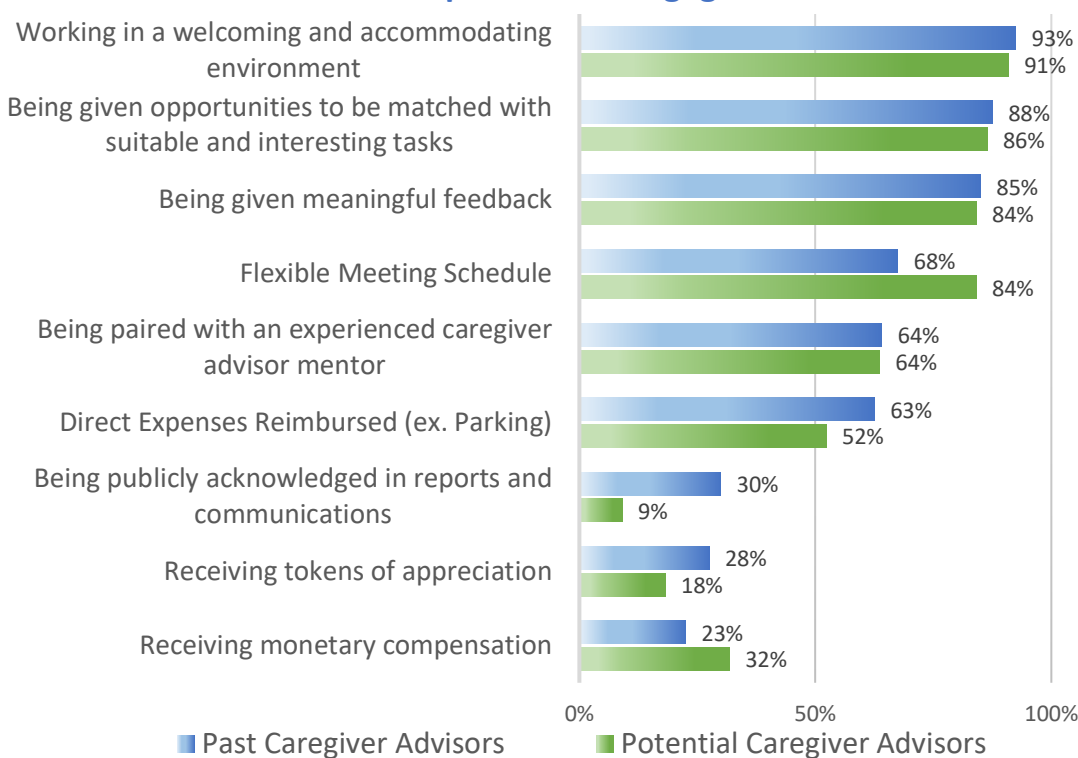3. Expectations of inexperienced service providers

When caregivers were asked what qualities they felt were important for engagement, a majority felt that working in a welcoming and accommodating environment was important (Figure 13). Similarly, most caregivers considered being given opportunities to be matched with suitable and interesting tasks and being given meaningful feedback as important.

While caregivers largely agreed on the importance of many considerations, some differences were of note: past caregiver advisors more commonly wanted to be publicly acknowledged in reports and communications, while more potential caregiver advisors felt having a flexible meeting schedule was important. These differences in opinion may highlight the difference in past involvement.

Figure 13. Percent of caregivers who felt the following considerations were important for engagement.

Consideration	Past Caregiver Advisors	Potential Caregiver Advisors
Working in a welcoming and accommodating environment	93%	91%
Being given opportunities to be matched with suitable and interesting tasks	88%	86%
Being given meaningful feedback	85%	84%
Flexible Meeting Schedule	68%	84%
Being paired with an experienced caregiver advisor mentor	64%	64%
Direct Expenses Reimbursed (ex. Parking)	63%	52%
Being publicly acknowledged in reports and communications	30%	9%
Receiving tokens of appreciation	28%	18%
Receiving monetary compensation	23%	32%

■ Past Caregiver Advisors   ■ Potential Caregiver Advisors

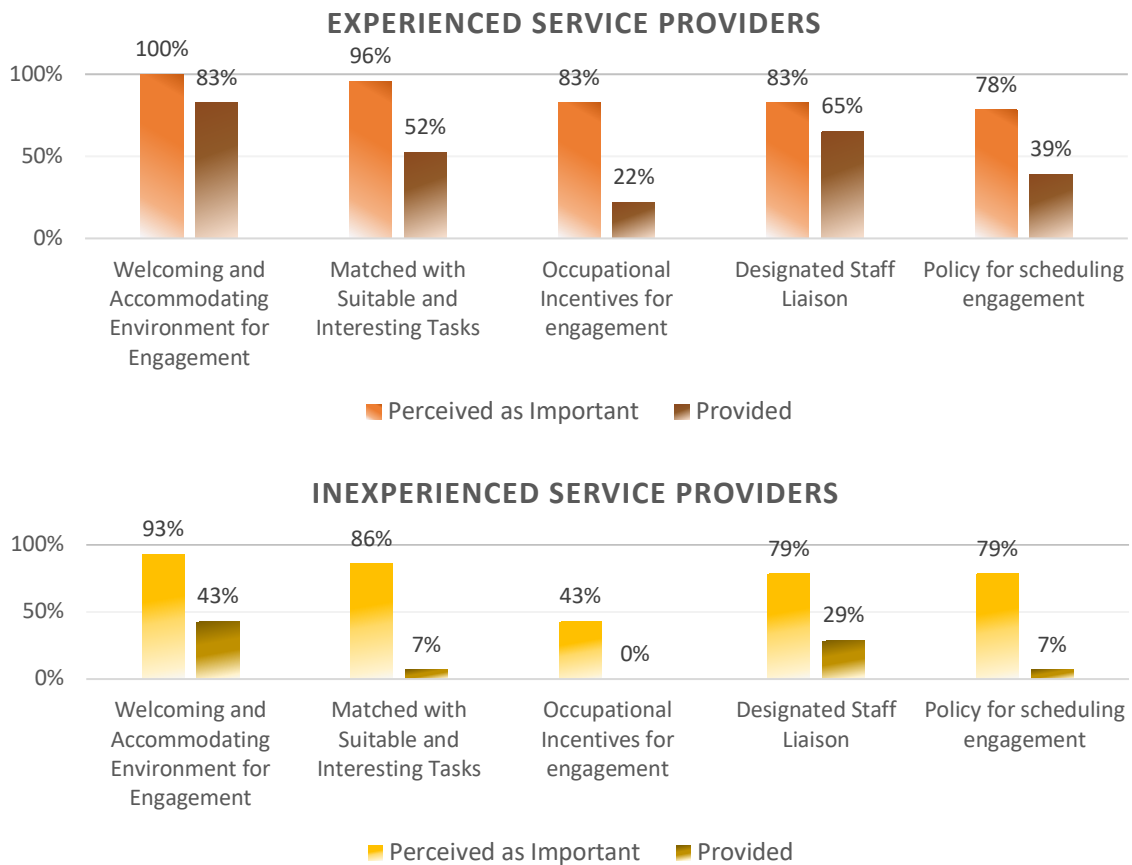## OTHER CONSIDERATIONS?

When caregiver advisors were asked what other considerations were important for engagement, past caregiver advisors reported that being recognized as an equal was important, as was being heard and respected, while potential caregiver advisors reported that it was important to be given clear roles, believe that involvement would result in real change, and being heard.

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Similar to caregivers, most service providers felt that a welcoming and accommodating environment was important for engagement; however, while most experienced service providers felt their organization provided such an environment, less than half of inexperienced service providers felt their organization provided it (Figure 14).

Being matched with suitable and interesting tasks was also considered important by a majority of service providers, however only half of experienced service providers and 7% of inexperienced service providers felt their organization provided these tasks. This perceived lack of suitable and interesting tasks may highlight a contributor for inexperienced service providers avoiding involvement in the past. For all items, however, less inexperienced service providers felt their organization provided them compared to experienced service providers.

Figure 14. Percent of service providers who felt the following considerations were important for engagement and provided by their organization.

EXPERIENCED SERVICE PROVIDERS

Consideration	Perceived as Important	Provided
Welcoming and Accommodating Environment for Engagement	100%	83%
Matched with Suitable and Interesting Tasks	96%	52%
Occupational Incentives for engagement	83%	22%
Designated Staff Liaison	83%	65%
Policy for scheduling engagement	78%	39%

INEXPERIENCED SERVICE PROVIDERS

Consideration	Perceived as Important	Provided
Welcoming and Accommodating Environment for Engagement	93%	43%
Matched with Suitable and Interesting Tasks	86%	7%
Occupational Incentives for engagement	43%	0%
Designated Staff Liaison	79%	29%
Policy for scheduling engagement	79%	7%

Both caregiver advisors and service providers, who have worked with advisors, were asked about their collaborative engagement experiences within their organizations (Figure 15). Most reported that their upper management supported and enabled working with caregiver advisors and that they were given timely information and recognition for their work. However, less felt that the role responsibilities were clear, or that they were given sufficient resources. Less than half reported having a previous negative experience with caregiver engagement.

Figure 15. Percent of participants who felt the following items were provided during their experience with engagement.
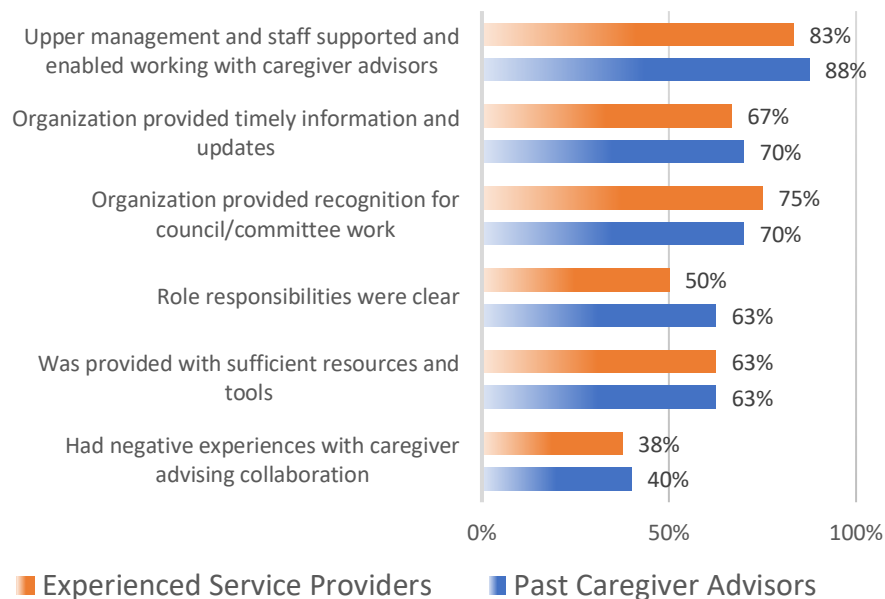
When service providers were asked if they were motivated to collaborate with caregiver advisors, all experienced service providers were motivated (100%). This was slightly higher than the inexperienced service providers who felt they would be motivated to collaborate with caregivers (85.7%).

HINDERENCES FOR SERVICE PROVIDERS INVOLVEMENT?

When asked what factors had hindered their work with caregiver advisors the most in the past, experienced service providers reported that a lack of clear roles/expectations, lack of communication, and limited availability has hindered their work with caregiver advisors.

Of the caregiver advisor directed questions, a majority of past caregiver advisors felt that they gained an understanding of an organization's culture and clinical terms, were given access to virtual communication tools, and that their work resulted in change (Figure 16). While most felt that they were treated as an equal contributor, there is room for improvement.

Figure 16. Percent of past caregiver advisors who felt the following items were provided during their experience with engagement.

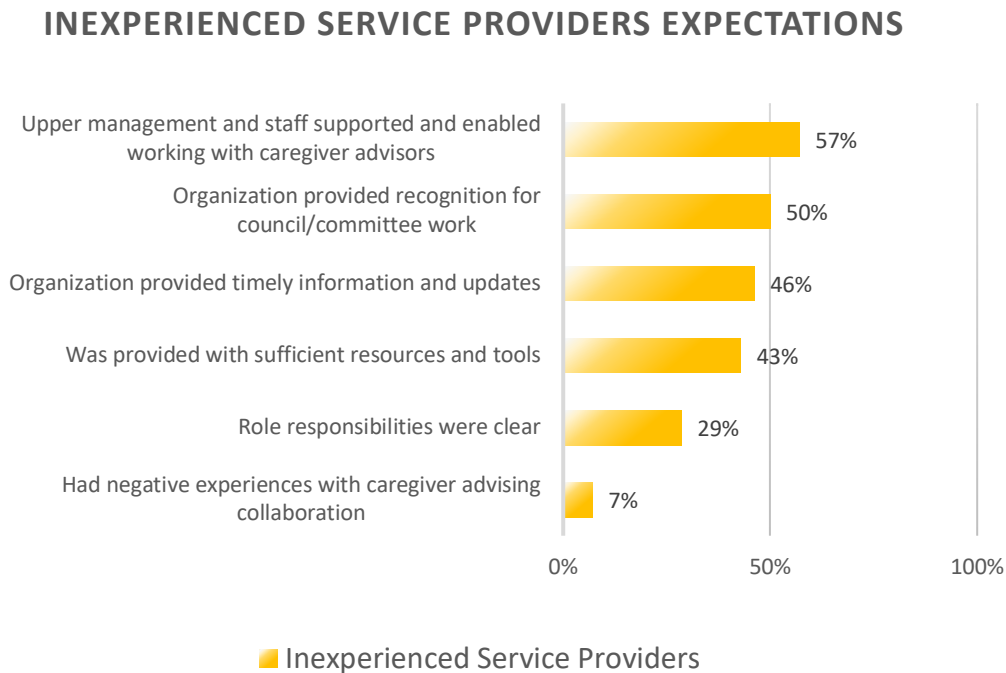PAST CAREGIVER ADVISORS

95% — Gained an understanding of organization's culture and clinical terms
85% — Given access to virtual communication tools
70% — Work resulted in real change
60% — Was recognized as an equal contributor
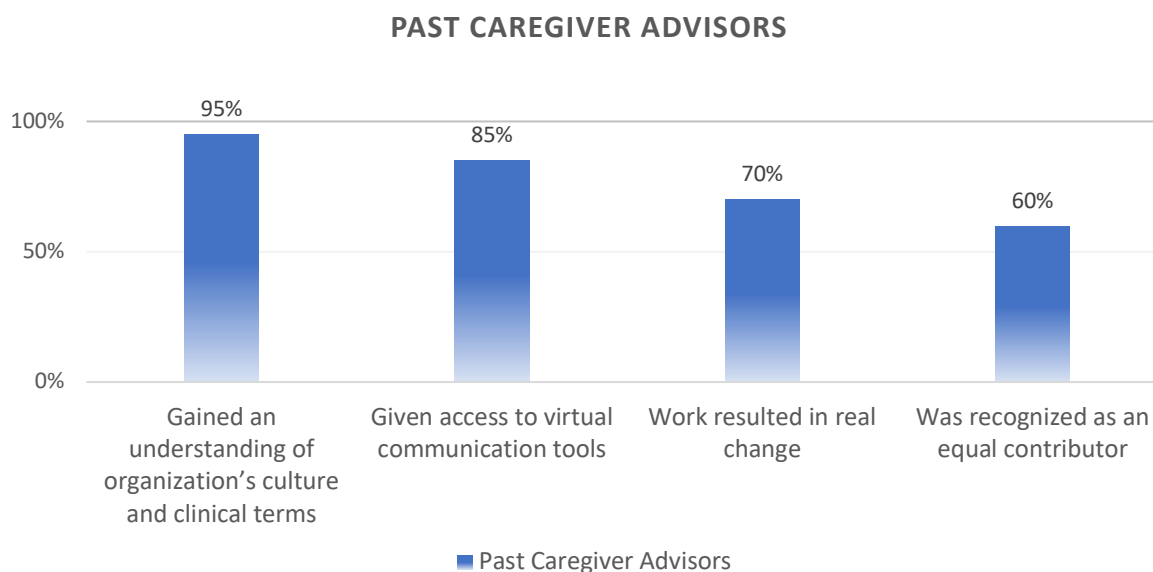
■ Past Caregiver Advisors

To understand the expectations of inexperienced service providers, we asked if they expected to have certain experiences happen during their potential involvements (Figure 17).

While more than half felt that upper management and staff would support working with caregiver advisors, only half felt they would gain recognition for their work and less than half felt they would be provided with timely updates and sufficient resources. Few felt that their roles and responsibilities would be clear. A majority did not expect to have a negative experience with collaboration engagement.

Figure 17. Percent of inexperienced service providers who felt the following items would be provided during their experience with engagement.

INEXPERIENCED SERVICE PROVIDERS EXPECTATIONS

Upper management and staff supported and enabled working with caregiver advisors — 57%
Organization provided recognition for council/committee work — 50%
Organization provided timely information and updates — 46%
Was provided with sufficient resources and tools — 43%
Role responsibilities were clear — 29%
Had negative experiences with caregiver advising collaboration — 7%
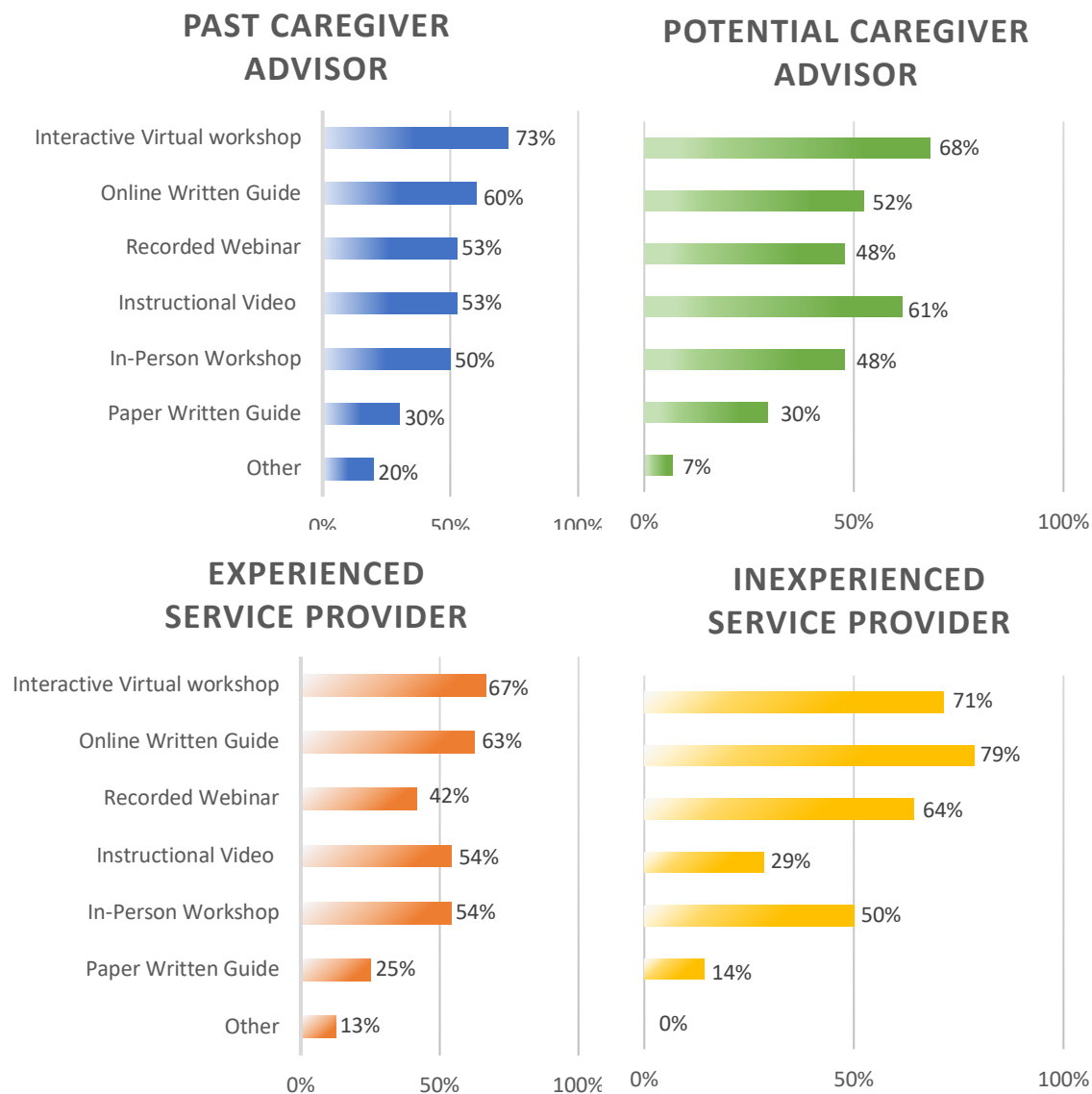
■ Inexperienced Service Providers

The difference in their expectations reported by inexperienced service providers and experiences of service providers (Figure 15) may demonstrate that inexperienced service providers doubt the support they would be given by their organization compared to the reality.

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KNOWLEDGE PRODUCTS

KNOWLEDGE PRODUCTS

When participants were asked which knowledge products they preferred, a majority chose the Interactive Virtual Workshop, followed by an Online Written Guide, although preferences varied between the different demographics (Figure 18). These results will guide our knowledge product creation.
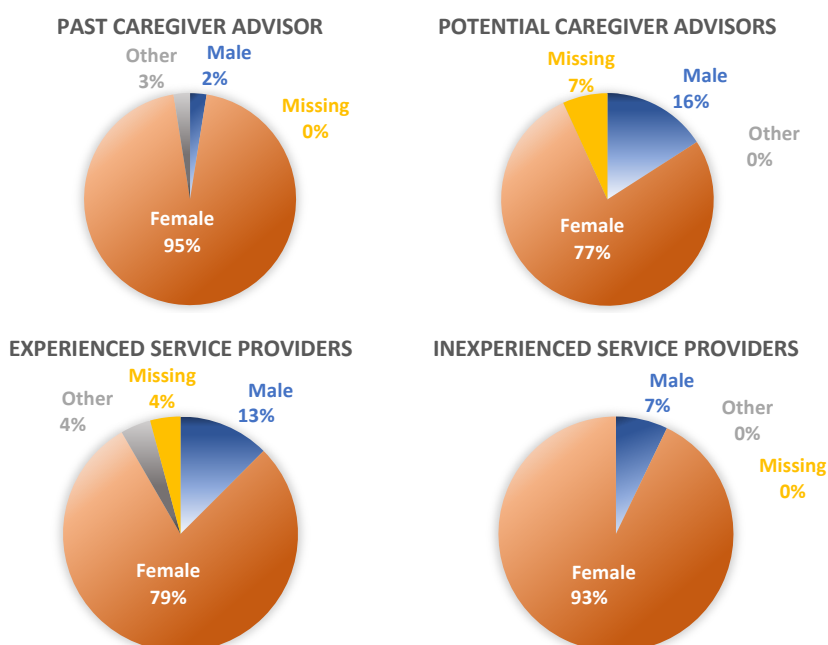
Figure 18. Percent of participants that preferred the following knowledge product format.

PAST CAREGIVER ADVISOR

Knowledge Product	Percent
Interactive Virtual workshop	73%
Online Written Guide	60%
Recorded Webinar	53%
Instructional Video	53%
In-Person Workshop	50%
Paper Written Guide	30%
Other	20%

POTENTIAL CAREGIVER ADVISOR

Knowledge Product	Percent
Interactive Virtual workshop	68%
Online Written Guide	52%
Recorded Webinar	48%
Instructional Video	61%
In-Person Workshop	48%
Paper Written Guide	30%
Other	7%

EXPERIENCED SERVICE PROVIDER

Knowledge Product	Percent
Interactive Virtual workshop	67%
Online Written Guide	63%
Recorded Webinar	42%
Instructional Video	54%
In-Person Workshop	54%
Paper Written Guide	25%
Other	13%

INEXPERIENCED SERVICE PROVIDER

Knowledge Product	Percent
Interactive Virtual workshop	71%
Online Written Guide	79%
Recorded Webinar	64%
Instructional Video	29%
In-Person Workshop	50%
Paper Written Guide	14%
Other	0%

LIMITATIONS

Despite our intention to survey Ontario caregivers, the generalizability of these findings may be limited due our inability to access certain Ontario caregiver populations. To begin, a majority of participants were female (Figure 19). As such, we were unable to investigate gender differences as originally intended.

Figure 19. Gender distribution of the sample

PAST CAREGIVER ADVISOR
Other 3%
Male 2%
Missing 0%
Female 95%

POTENTIAL CAREGIVER ADVISORS
Missing 7%
Male 16%
Other 0%
Female 77%

EXPERIENCED SERVICE PROVIDERS
Other 4%
Missing 4%
Male 13%
Female 79%

INEXPERIENCED SERVICE PROVIDERS
Male 7%
Other 0%
Missing 0%
Female 93%

The survey was conducted exclusively in English, limiting access to Ontario caregivers who are non-English speaking. Participants were nearly exclusively from Southern Ontario. In addition, the named organization of the participant was not collected and, therefore, results could not be compared within or between the same organizations.

CONCLUSIONS

While some caregiver advisors and experienced service providers have had quality collaboration previously, several gaps remain to ensure meaningful collaboration is sustainable and easier to achieve. It should be acknowledged that several of the gaps are resources intensive to solve. Within the context of this project, however, three of the main gaps were recognized that could be addressed by knowledge products:

1. Training caregiver advisors how to share their personal experiences.

2. Training engagement skills to service providers.

3. Giving caregiver advisors and service providers opportunities to be matched with suitable and interesting tasks.

Phase two of this project contained in the next section of this report investigated these questions from the perspective of expert caregiver advisors and experienced service providers.

For future research projects, we would recommend studying the following:
- Gender Differences
- Effective evaluation to study engagement materials for sustainability

PHASE TWO: COLLABORATION EVENT

VIRTUAL FOCUS GROUP METHODS

Once the survey results were collected and analyzed, prominent needs were identified based upon level of importance given to the topic and the lack of current practices and preparedness for meaningful engagement. Of these, three topics were considered for discussion during the virtual focus group:

1. Training caregiver advisors how to share their personal experiences.
2. Training engagement skills to service providers.
3. Giving caregiver advisors and service providers opportunities to be matched with suitable and interesting tasks.

The research team then developed a virtual focus group questionnaire by pulling questions from selected topics that focused on the practical skills and advice that could be used to craft knowledge products. The questions were reviewed by two caregiver advisors to ensure the importance and relevance of the original topics were maintained. Additional questions were included to determine which knowledge product formats were recommended for the given topic. The following phase two materials (invitation to key experienced stakeholders; background information/daily agenda/focus question, consent form, confidentiality agreement, participant) were submitted to The Royal for Ethics Board approval. When approval was granted, a package of prep information was delivered to the participants one week before, which explained the process of the focus group, a brief background of the project, and outlined the questions they would be asked to answer.

Due to COVID-19 restrictions, the originally planned in-person collaborative symposium was changed to a virtual focus groups format via Zoom. There were three 1.5-hour sessions held on consecutive days. During the sessions, preparatory information was presented to the participants along with two questions focused on each topic and which specific knowledge transfer format would be best utilized for the solutions they provided.

After outlining each question, participants were split into groups of four by a breakout room mechanic available through Zoom for small group discussion. After their small group discussion of approximately 10-minutes, participants reconvened and were given an opportunity to share solutions and suggestions with the full group. On average, sixteen participants were in attendance each day and contributors were sent an anonymous online exit survey at the end of the three days for last thoughts. All suggestions, ideas, and solutions were recorded to be used as reference materials in the development of useful aids, tools and products.

Day One Virtual Focus Group Topic - *How to share their personal experiences*

Both caregiver advisors and service providers felt it was important for caregiver advisors to be trained on how to share their personal experiences constructively (Figure 11). We selected this training topic due to the clear need, sensitive nature, and unique challenges in the mental health setting. During this session, we asked:

1. What elements or qualities of a personal experience make certain experiences important to share?

2. What approaches or practices can caregiver advisors use to constructively share important personal experiences?"

Day Two Virtual Focus Group Topic - *Service provider engagement skill training*

The survey highlighted that both experienced and non-experienced service providers agreed that within their organizations, caregiver engagement skill training was considered important (Figure 12). However, we recognized that *engagement skill training* could include a variety of topics and we required a more specific definition to create knowledge products. The session questions were:

1. What **teachable skills** do service providers need to engage caregiver advisors in their organization that would benefit collaboration?

2. What **methods** can be used to teach these skills to service providers while keeping in mind possible resource limitations?

Day Three Virtual Focus Group Topic - *Matched with suitable tasks*

Being given opportunities to be matched with suitable and interesting tasks was considered important for caregiver collaboration by all of those who were surveyed (Figures 13 and 14). Similarly, the definition of *suitable and interesting tasks* needed to be explored. The two final questions asked for this session were:

1. How would you **define** a 'suitable and interesting task' from the perceptive of a caregiver advisor and the perspective of a service provider?

2. How can organizations **provide** suitable and interesting tasks that match the skills or interests of the caregiver advisor or service provider?

The discussion for each topic was extensive and expanded beyond the original expectations of the crafted questions. All results were recorded and summarized into bullet points. The results below the summarized topic of discussion.

> **"It is a gift to tell the story."**

Day One Topic - *How to share their personal experiences*

"What elements or qualities of a personal experience make certain experiences important to share?" …as a Caregiver Advisor:

1. The experience should be focused on a **specific goal by sharing it**.

2. The experience should focus on **systematic change**

3. The experience should be **generalizable.**

4. The experience should be **specific to audience and relevant topic at hand.**

5. The experience should be **hopeful.**

6. The experience should be **solution focused**.

7. The experience should include elements that were **positive.**

8. The experience should **include 'wins' for the service providers** for better uptake of the experience.

9. The experience should include **long-term impacts**.

> **"Telling a story is not labour or emotional neutral."**

"What approaches or practices can caregiver advisors use to constructively share important personal experiences?"

1. **Remember that advisory is different from advocacy;** the retelling should focus on advisory goals.

2. **Be mindful**: Recognize that the story is personal and there are other perspectives.

3. **Avoid defensiveness** while telling the experience and listening to others.

4. During the retelling, **adopt business strategies** to highlight organization benefits that would be possible if the problem was addressed differently.

5. Keep the retelling **fact-based and include background Information,** such as specific dates of the experience, alterative solutions, and supplementary resources for further context.

6. Include only **teachable moments.**

7. Ensure the retelling **respects the privacy of your loved one.**

8. Consider **connecting emotionally** to listener for better impact.

9. Be considerate of **potential audience triggers. Share compassionately.**

10. **Have a mentor or other support** to practice and develop your retelling skills.

11. **Be aware of your readiness** and emotional state. Recognize that retellings are **taxing gifts and require emotional investment.**

12. **Consider the organization** you will be sharing with and determine if they are willing to be accountable to your input.

13. Outline how the experience **affected you and your loved one.**

14. Spend time **developing your communication and presenting skills by practicing and reflecting**.

"Training needs to be co-designed and co-presented."

"What teachable skills do service e providers need to engage caregiver advisors in their organization that would benefit collaboration?

1. Service providers need **engagement training** to define collaboration and understand the value of caregiver advisor input.

2. Service providers need **effective communication** by using clear and accessible language.

3. Service providers need **authenticity and empathy** that allows for patience with caregiver advisors.

4. Service providers need **foundational organizational skills**, such as meeting facilitation meeting preparation, feedback delivery, and how to have conversations about compensation and honorariums.

5. Service providers need **active listening skills**.

6. Service providers need **self-awareness and cultural sensitivity**.

7. Service providers need training on **relational dynamics, trust building, and validation skills** to support them.

8. Service providers need **trauma-informed training and mental health first aid**.

9. Service providers need **leadership skills** to lead engagement.

10. Service providers need **technology training** to limit engagement barriers.

11. Service providers need training on **ethics of engagement, confidentiality, and informed consent**.

"What methods can be used to teach these skills to service providers – keeping in mind possible resource limitations?"

1. **Standardized engagement training** to ensure the training fulfills the basic requirements of engagement with adult learning principles.

2. **Roleplaying** caregiver stories and engagement skills. A laboratory course with expert caregiver advisors giving live demonstrations and one-on-one practice.

3. **Co-facilitation** opportunities to expand the roles of caregiver advisors to partner with service providers to co-facilitate and lead engagement together.

4. **Caregiver advisor mentorships** with their peers and service providers. For example, shadowing interactions for a day and providing debriefs on how effective the collaboration efforts were.

5. **Prescriptive Material:** Service providers and caregiver advisors are limited on time which means knowledge products should be prescriptive and easily shared.

6. **Incentives** for training or professional development.

7. **Partnerships with other Communities:** Partnership with other organizations to scale this project.

8. Training manuals and caregiver **mandatory training** for all staff once per year.

9. Provide **feedback on engagement** by having satisfaction / experience surveys that are co-created.

10. Host **casual events** to build equality, such as yearly dinners with caregivers and service providers for a relaxed, collaborative experience.

"Caregiver advisors bring their skill sets and experiences to provide expertise and for quality improvement"

"How would you define a 'suitable and interesting task' from the perceptive of a caregiver advisor and the perspective of a service provider?"

1. The task must be **attainable** with few barriers and allow for a follow-through.

2. The task must be **important**. Avoid menial tasks, such as fundraising or newsletter creation.

3. The task should provide **recognition** from involvement.

4. The task must **align with the values, interests, skills, and availability** of the caregiver advisor or service provider.

5. The task needs **meaningful and respectful discussions** that hold value for those on the committee.

6. As professionals, caregiver advisors should be **provided incentives** through payment.

7. The task should be **a priority** for service providers and their organization to move towards their goals.

> **"Caregivers are compensated for their time by witnessing changes."**

"How can organizations provide suitable and interesting tasks that match the skills or interests of the caregiver advisor or service provider?"

1. **Explore gaps** in the current services from personal experiences of caregiver advisors and service providers to find opportunities for tasks through needs assessment and focus groups.

2. To match caregiver advisors to suitable tasks, **use an inventory** of their values, interests, and available time, as well as the opportunities provided to allow for transparency of opportunities. Survey advisors to find out what their skills are. Some organizations have a database of pressing concerns that need to be addressed that caregiver advisors can access and volunteer for.

3. **Interview potential caregiver advisors** to assess if they have the skills and emotional stability required for the task.

4. Provide **clear expectations** to determine needs and identify the exact job and skills needed with time commitments. All of these details must be determined beforehand.

5. Have **an emotional support person** attached to the committee as these topics can be triggering to process.

6. Have a paid **staff liaison** to properly align caregiver advisors with tasks.

7. Caregiver advisors must be **involved at the conception** of the project.

8. Provide opportunities for a **variety of involvement,** from those that dedicate time in a committee to those that have less availability but can be surveyed through the phone for their input on a specific concern.

9. Provide **ongoing learning experiences** for caregivers so they can learn new skills to expand the tasks that they are suitable for.

PHASE THREE: KNOWLEDGE PRODUCTS

KNOWLEDGE PRODUCTS

Knowledge product development will be taking place from March 2021 to July 2021. The products should be publicly available by September 2021.

The report will be updated by July 2021 to include the details of phase three.

APPENDIX A.

ADDITIONAL ACKNOWLEDGEMENTS

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Meghan Perkins	

To be included in the sample, participants had to be at least 16 years old, be able to access the online survey (English), and reside in Ontario, Canada, at the time of the survey. No limitations were set on how long ago the experience as a caregiver advisor or service provider occurred.

Surveys completed by residents outside of Ontario (N=2), or surveys that were incorrectly selected for their demographic (N=1), were removed. Surveys that provided no additional information beyond approved consent were removed (N=26) and surveys that did not provide answers for our main questions of interest were considered incomplete and removed (N=22). Of the 170 correctly initiated, 122 surveys were completed (completion rate 72%). By using anonymous links, survey response rates could not be determined.

Figure 1. Sample Inclusion Flow Chart

Consented Surveys
N = 173

REMOVED
Non-Ontario Resident (N=2)
Incorrect Survey Selection (N=1)

Correctly Consented Survey
N = 170

REMOVED
Consented but not Initiated
Surveys (N=26)

Initiated Survey
N = 144

REMOVED
Incomplete Surveys (N=22)

Completed Surveys
N = 122
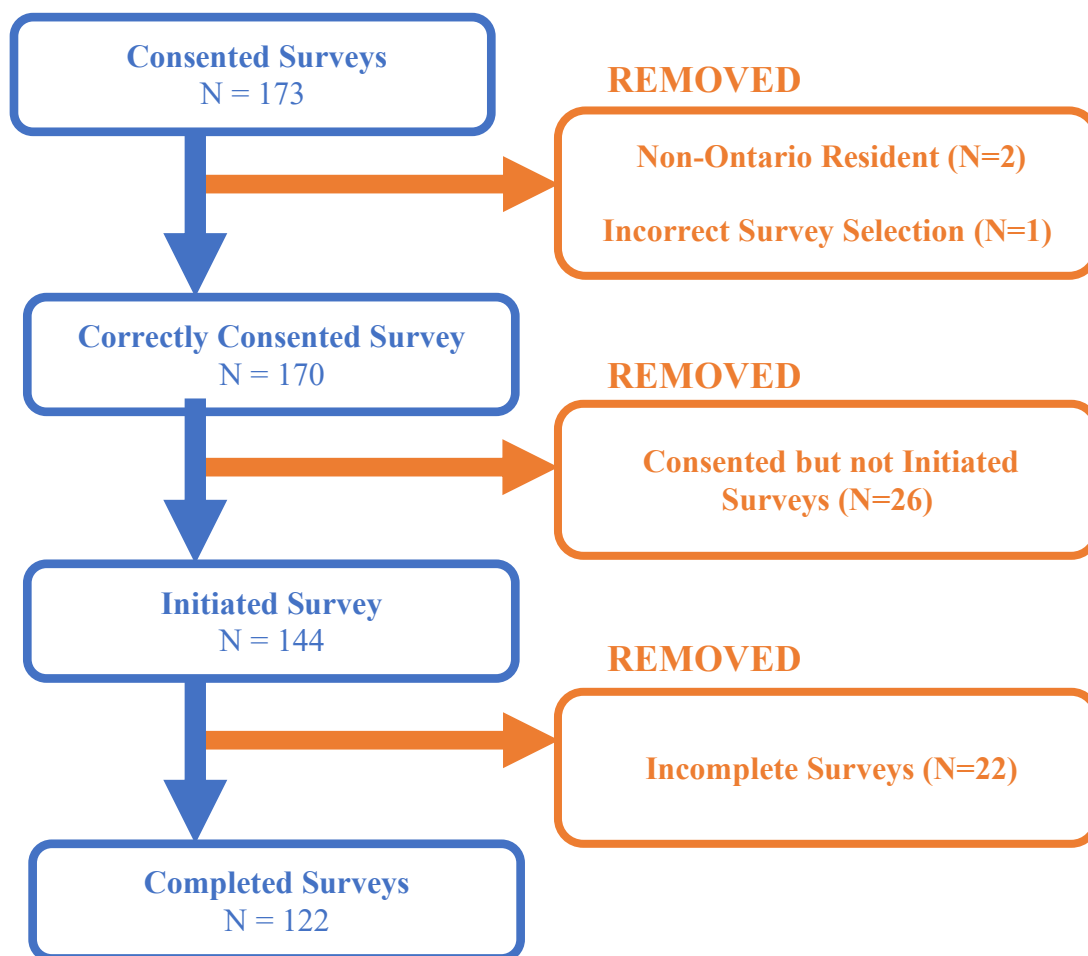
The final sample of caregivers comprised 84 individuals, of which n=40 were past caregiver advisors (Mean age = 62 years, SD=10 years) and n=58 were potential caregiver advisors (Mean age =58 years, SD=11 years).

Table 1. Caregiver demographics

Demographic	Past Caregiver Advisor		Potential Caregiver Advisor	
	(n=40)	Valid %	(n=44)	Valid %
Gender				
Male	1	2.5	7	15.9
Female	38	95.0	34	77.3
Other	1	2.5	0	0.0
Missing	*0*	*0*	*3*	*6.8*
Employment Status				
Unemployed	1	2.5	1	2.3
Full-time employment	6	15.0	16	36.4
Part-time employment	10	25.0	3	6.8
Retired	12	30.0	10	22.7
Volunteer	5	12.5	1	2.3
Other	5	12.5	9	20.5
Missing	*1*	*2.5*	*4*	*9.1*
Highest Education Level				
High school completed	3	7.5	1	2.3
Some college / university	3	7.5	5	11.4
College or University	33	82.5	35	79.5
Missing	*1*	*2.5*	*3*	*6.8*
Locations Advised or Accessed				
Community Organization	22	55.0	28	63.6
Hospital	25	62.5	37	84.1
Government Agency	11	27.5	14	31.8
Other Healthcare or promotion agency	8	20.0	16	36.4
Other setting	2	5.0	15	34.1
Missing	-	-	-	-

The final sample of service providers comprised 38 individuals, of which n=24 had experience working with caregiver advisors (Mean age=50 years, SD=13 years) and n=14 had no experience working with caregiver advisors (Mean age=39 years, SD=12 years).

Table 2. Service Provider Demographics

Demographic	Experienced Service Providers		Inexperienced Service Providers	
	(n=24)	Valid %	(n=14)	Valid %
Gender				
Male	3	12.5	1	7.1
Female	19	79.2	13	92.9
Other	1	4.2	0	0.0
Missing	*1*	*4.2*	*0*	*0.0*
Employment Position				
Clinical Professional	5	20.8	8	57.1
Executive Leadership	2	8.3	0	0.0
Management	2	8.3	2	14.3
Community Support	4	16.7	2	14.3
Other	10	41.7	2	14.3
Missing	*1*	*4.2*	*0*	*0.0*
Employment Organization(s)				
Community Organization	9	37.5	2	14.3
Hospital	14	58.3	10	71.4
Government Agency	2	8.3	0	0.0
Other Healthcare or promotion agency	9	37.5	1	7.1
Other setting	1	4.2	1	7.1
Missing	-	-	-	-
Organization's Specialties				
Mental Health	22	91.7	14	100.0
Substance Use and Concurrent Disorders	18	75.0	11	78.6
Other	6	25.0	2	14.3
Missing	-	-	-	-
Experience Roles				
Staff Liaison	13	54.2	-	-
Council Member	7	29.2	-	-
Council Co-Chair	5	20.8	-	-
Project Manager	4	16.7	-	--
Committee Member for Specific Project	11	45.8	-	-
Other	4	16.7	-	-
Missing	-	-	-	-

The final sample of Loved One of the Caregivers included 84 individuals, of which n=40 were the loved one of past caregiver advisors and n=58 were the loved one of potential caregiver advisors.

Table 3. Demographics of Caregivers with a Loved One Living with a Mental Illness

Demographic	Past Caregiver Advisor		Potential Caregiver Advisor	
	(n=40)	Valid %	(n=44)	Valid %
Relation to Caregiver				
Parent	7	17.5	3	6.8
Spouse	2	5.0	7	15.9
Children	22	55.0	20	45.5
Sibling	2	5.0	1	2.3
Other	6	15.0	10	22.7
Missing	*1*	*2.5*	*3*	*6.8*
Diagnosis(es)				
Schizophrenia	14	35.0	8	18.2
Bipolar	11	27.5	14	31.8
Borderline Personality Disorder	4	10.0	5	11.4
Depression / Anxiety	11	27.5	19	43.2
Substance Use Disorder	7	17.5	11	25.0
No Formal Diagnosis	3	7.5	1	2.3
Other	10	25.0	17	38.6
Missing	-	-	-	-
Live with Caregiver				
Yes	18	45.0	26	59.1
No	14	35.0	11	25.0
Sometimes	7	17.5	4	9.1
Missing	*1*	*2.5*	*3*	*6.8*
Recovery Status				
In-Crisis	3	7.5	3	6.8
In Progress	9	22.5	14	31.8
Complete but on-going care required	13	32.5	9	20.5
Is not participating	1	2.5	5	11.4
Other	13	32.5	7	15.9
Missing	*1*	*2.5*	*3*	*6.8*