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# Building a Framework for Meaningful Family Caregiver Engagement

## Environmental Scan Summary Report

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### Abstract

The purpose of this report is to inform survey development for the project 'Building a Framework for Meaningful Family Caregiver Engagement'. First, we introduce the motivations for the survey. Next, we discuss the methods used for the report before summarizing our findings. For convenience, the results are separated by the phases of the family caregiver advisor lifecycle before exploring unique mental health findings.

## Introduction

The purpose of the project is to create a framework of knowledge products that guides the relationship between family caregiver advisors and care provider organizations to create meaningful and collaborative partnerships that lead to positive changes in hospital and community-based mental health and addiction organizations based on evidenced-based practices that align with the directions, strategies, and priorities of regional, provincial, and federal health teams.

Firstly, we aim to understand the interests, motivations, and needs met for experienced family caregiver advisors throughout the lifecycle of their engagement with a hospital and/or community-based mental health organization. Secondly, we aim to understand the interests and needs of potential future family caregiver advisors, including what incentives would motivate them to serve as advisors and what barriers would stand in their way. Finally, we aim to assess current levels of hospital and community-based mental health organization interest and maturity in engaging family caregiver advisors within the Champlain region aiming to uncover pathways, build a roadmap, compile a resource tool kit, and offer practical guidance for all to build value-creating capability and capacity within their organizations.

## Methods

Two researchers conducted a brief scoping review of available resources and publications about family caregiver advisor and mental health organization engagement, focusing on information and resources that currently exist. In order to be considered within the scope of our review, articles must have focused on client/family member advisor engagement separately from client/family member participation in individual healthcare decisions. No limitations were placed on the location, target demographic, or published year. Article collection was halted once topic saturation was reached.

Once an article was determined to meet the scan inclusion criteria, all relevant information was summarized into specific topic headings by one of the researchers. These summarizations were further reviewed and logically grouped by the second researcher. Article summaries were amalgamated into a singular report. After reflecting upon common themes, new topic categories were created for items that were placed into a temporary general category during the summary phase. Information that did not benefit the purpose of survey creation was not included but is available upon request. More detailed information from these summaries can be found in the Appendix.

## Articles

**Table 1:** Resources from Organizations

<b>Guide</b>	<b>Location / Year</b>	<b>Target Audience</b>	<b>Topics</b>
Family Engagement: Resource Guide <sup>1</sup>	Ontario, Canada 2019	Family members of children and youth <b>mental health</b> clients.	<ul style="list-style-type: none"> <li>- Benefits of caregiver engagement</li> <li>- Potential projects and roles for caregiver advisors</li> <li>- Best practice for caregiver advisor engagement</li> <li>- Program evaluation step-by-step with caregiver advisors</li> <li>- Caregiver advisor recruitment and on-boarding</li> <li>- Organization's culture and practices that allow for caregiver advisors</li> </ul>
Ontario's Patient Engagement Framework <sup>2</sup>	Ontario, Canada 2017	Patients and caregivers in general healthcare settings.	<ul style="list-style-type: none"> <li>- Service provider culture to enable engagement</li> <li>- Information on personal-level, program-level, and policy-level engagement</li> <li>- Lists the guiding principles for engagement</li> </ul>
A Patient and Family Advisory Council Workplan: Getting Started <sup>3</sup>	Maryland, USA 2013	Patients and caregivers in general healthcare settings.	<ul style="list-style-type: none"> <li>- Fill-in-the-blanks steps on how to start a family and patient council</li> <li>- List of desired caregiver advisor qualities</li> <li>- How to sustain council success and engagement</li> </ul>
A Resource Toolkit for Engaging Patient and Families at the Planning Table <sup>4</sup>	Edmonton, AB 2014	Patients and caregivers in general healthcare settings.	<ul style="list-style-type: none"> <li>- Summary of advisor engagement benefits</li> <li>- Assess agency readiness for engagement</li> <li>- Advice on advisor engagement to avoid problems, improve staff culture, and have successful engagement</li> <li>- Advisor recruitment, interviewing, and sustainability</li> <li>- Staff Liaison position and qualities</li> </ul>
Strategy 1: Working with Patient and Families and Advisors (Implementation Handbook) <sup>5</sup>	Maryland, USA 2017	Patients and caregivers in general healthcare settings.	<ul style="list-style-type: none"> <li>- Gives 5 steps for implementing patient and family advisors with specific suggestions</li> <li>- Specific tools to enable engagement</li> <li>- Offers additional information on working with advisors for specific projects</li> </ul>
Tips for how to be an Effective Patient or Family Advisor: A Beginning List <sup>6</sup>	Maryland, USA 2010	Patients and caregivers in general healthcare settings.	<ul style="list-style-type: none"> <li>- List of desired qualities for effective family advisors</li> </ul>
Creating and Sustaining Patient and Family Advisory Councils: Guides for Common Challenges <sup>7</sup>	Ontario, Canada 2017	Existing caregiver and patient advisors in general healthcare settings.	<ul style="list-style-type: none"> <li>- Focuses on how to get a diverse advisor council</li> <li>- Offers specific tools to find members</li> </ul>

**Table 1 Continued: Resources from Organizations**

<b>Guide</b>	<b>Location / Year</b>	<b>Target Audience</b>	<b>Topics</b>
The Ottawa Hospital Cancer Program Patient & Family Advisory Council: Frequently Asked Questions (FAQ's) <sup>8</sup>	Ontario, Canada N/A	Caregiver and patient advisors for cancer program council.	- Hand-out style information for those interested in becoming part of the cancer program advisory council
Rules of Engagement: Lessons from PANORAMA <sup>9</sup>	Ontario, Canada 2016	Caregiver and patient advisors in a general healthcare setting.	- Advice for quality patient advisor engagement - Lists engagement models - Lists rules for healthy dialogue
Should Money Come into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants <sup>10</sup>	Ontario, Canada 2015	Caregiver and patient advisors in a general healthcare setting	- A detailed checklist to determine project compensation - Discusses merits and detriments to providing compensation for advisory positions

**Table 2: Journal Articles**

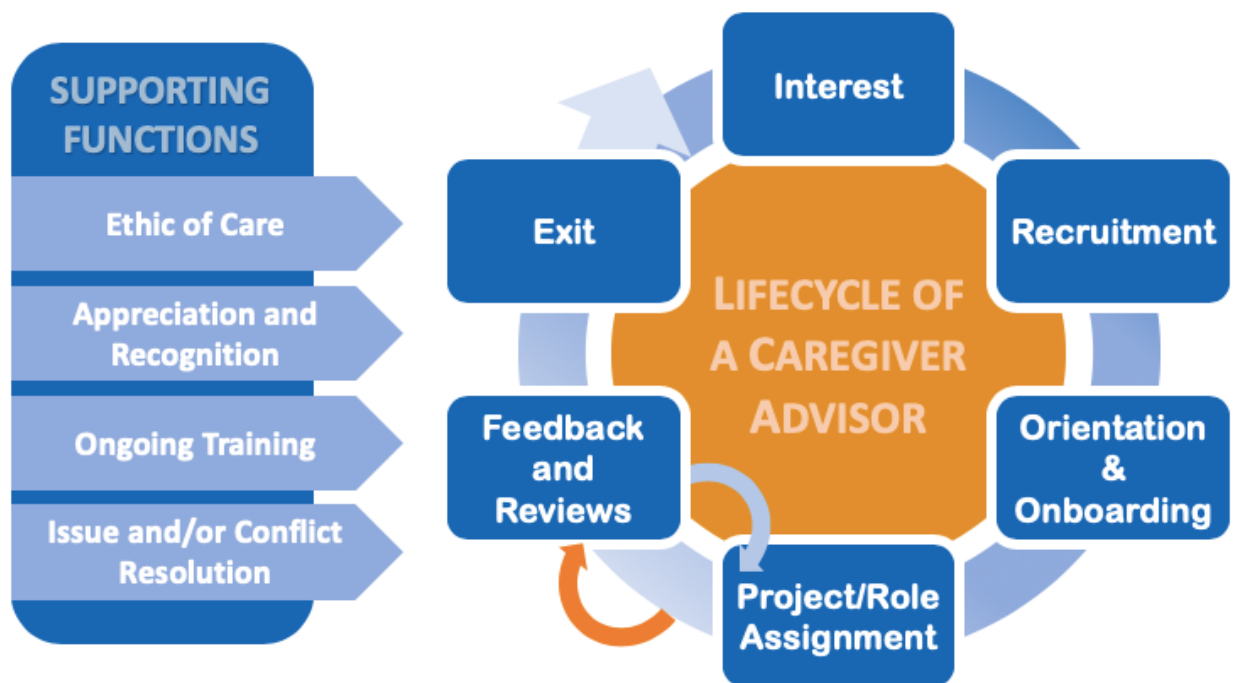
<b>Article</b>	<b>Location / Year</b>	<b>Target Population</b>	<b>Topics</b>
<i>Gateway to FamilySmart™ Evidence (Edition 3): Collaborative Research and Evaluation</i> <sup>11</sup>	Vancouver, BC 2014	Family members of children and youth <b>mental health</b> clients.	- Benefits of collaborative research - Limitations of collaborative research
Identifying barriers to mental health system improvements: An examination of community participation in assertive community treatment programs <sup>12</sup>	Ontario, Canada 2011	Assertive Community Treatment (ACT) programs for community based <b>mental health</b> services	- Examines ACT compliance of using community advisory bodies by perspective of the service provider - Barriers to using community advisory boards
Twelve principles to support caregiver engagement in health care systems and health research <sup>13</sup>	Ontario, Canada 2019	Caregiver advisors in a general healthcare setting.	- Twelve themes that summarize recommendations from lived experiences with/as caregiver advisors
Community involvement in the development and implementation of chronic condition programmes across the continuum of care in high- and upper-middle income countries: A systematic review <sup>14</sup>	International, 2020	Community involvement programs including advisors, partners, community members, and consumers for <b>mental health</b> and other chronic illnesses.	- Challenges and 'lessons learned' from mental health community programs - Challenges and 'lessons learned' from other chronic conditions programming - Demonstrates a difference between mental health committees and other chronic illness committees.

## Results

### Family Caregiver Advisor Engagement Lifecycle

For ease of view, literature findings have been organized to illustrate the lifecycle of engagement throughout the lifespan of an organization’s relationship with a family caregiver advisor, starting from a starting point of a family caregiver’s interest to engage as an Advisor.

Illustrated in the figure below, a family caregiver advisor’s relationship and engagement with an organization can be viewed as evolving according to the following lifecycle: from the point of their interest, through recruitment, orientation and onboarding, role/project assignment(s), feedback/ reviews, and to the point of exit. Organizational activities that invite and help build relationships with family caregiver advisors and engage them are mapped against each step in the lifecycle. Also illustrated to the left of the lifecycle, are the conditions and activities researched organizations cultivate to foster strong and lasting relationships with family caregiver advisors throughout the lifespan of their engagement.



**Figure 1.** Family Caregiver Advisor Engagement Lifecycle

A more detailed description of each lifecycle phase and supporting conditions and activities follow.

## Family Caregiver Advisors' Interests

This section highlights insights gleaned from literature review material that speak to the interests, motivations, and benefits family caregiver advisors derive through their engagement with mental health organizations, as well as, what important needs must be met, and barriers overcome, for them to engage and sustain their engagement.

### Family Caregiver Advisor Engagement Interests, Motivations, and Benefits

Research literature highlights that family caregiver advisors value engagement with mental health organizations as it provides them with the opportunity to:

- Connect with other families, staff, agency leaders, and services to create a supportive network for information sharing and overcoming challenges<sup>1,4</sup>
- Learn and improve their skills<sup>4</sup>
- Improve their personal health and well-being<sup>1</sup>
- Share their perspective<sup>13</sup>
- Increase their knowledge of health system and policies<sup>1,4</sup>
- Contribute to meaningful change in the agency<sup>1,4</sup>
- Improve quality and safety of services<sup>4</sup>

The literature highlights that family caregiver advisors value engagement assignments that:

1. Match their interests and skill sets
2. Are meaningful in the scale and scope of difference they can make

### Barriers of Collaborative Efforts for Family Caregiver Advisors

## Health Organizations that Engage Family Caregiver Advisors Lifecycle

### Recruitment

The second phase in the lifecycle of family caregiver engagement is recruitment. Recruitment should be one of the first steps of a collaboration project to allow for caregivers to become involved early in the project<sup>5,13</sup>.

When planning to recruit and engage Family/Caregiver advisors, the literature consistently highlights the importance of aiming to ensure balanced representation of Advisors in alignment with the organization's diverse client population and range of care experiences<sup>4,5,7,9,13,14</sup>. For example, one guide highlighted their efforts to balance their council with representation

reflecting both overly negative and overly positive experiences to ensure the expression of a full range of voices<sup>7</sup>. Others, referred to their practice of hiring multiple advisors in order to be able to draw upon multiple perspectives<sup>4,5</sup>.

## Recruitment Process

The following are common pre-recruitment or planning practices prior to an organization's recruitment of family caregiver advisors:

1. Draft a mission statement and bylaws based upon project priorities<sup>3,5</sup>
2. Determine requirements, personnel, and resources needed to be provided by the organization while ensuring organizational members are on the council, including participant compensation<sup>1,4,5,7,10</sup>.
3. Determine eligibility criteria for potential family caregiver advisors or researchers. These can include specific demographic qualities, skills, knowledge, and use of target services based on project requirements<sup>1,3,5,7,8</sup>. General ideal traits include:
  - a) Lived-Experience, Available Time, and Energy<sup>1,4-7</sup>
  - b) Positive Intentions, Outlook, and Confidence<sup>4-6,13</sup>
  - c) Well Developed Interpersonal Skills<sup>2-7</sup>
  - d) Supportive with Well Developed Collaborative Skills<sup>3-7</sup>
  - e) Authentic and Willing to Share their Perspective<sup>3-7</sup>
  - f) Responsible and Respectful<sup>4-6</sup>
  - g) Healthy Coping Skills<sup>4,5</sup>
  - h) Able to see beyond themselves, including their expectations and perspectives<sup>3-6</sup>
4. Determine a selection process. This process can include using interviews, formal forms, and/or simply informal agreements<sup>1,5</sup>. Consider using inclusive, culturally sensitive practices, such as using multi-lingual invitations, translators, allowing for religious practices, and accessible meeting places<sup>1</sup>.

Where appropriate, conduct interviews drawing from staff liaison(s), council's key contract, partner family advisors, senior leadership, and front-line staff to screen applicants, as appropriate for the scale and scope of the work to be done<sup>2,5</sup>. Typically, these are hosted by a person of power, like the Chair or Vice Chairperson, and done on the phone or in-person.<sup>7</sup>

5. Select recruitment approach:
  - a. Using internal means like a digital database with a list of potential advisors with their names, contact info, preference for involvement, and interests can make tracking and opportunity matching easier for targeted communications<sup>3</sup>

- b. Advertise the position using a variety of different means both internally and externally<sup>1,4,5,7,9</sup>. It is recommended to use creative solutions to actively target specific populations since normal, local advertising for volunteers will not give a diverse council<sup>1,7</sup>.
6. Create recruitment material. Guidance in literature review material suggest recruitment materials be role/project specific, easy to use, comprehensive, and translated with images to reflect the diversity desired<sup>1,5,7,8</sup>.

## Orientation and Onboarding

The level of orientation will depend upon the specific role of the new caregiver advisors<sup>1,4,5</sup>. Long-term commitments will require a more comprehensive orientation than caregivers that are only partaking in shorter roles, but all orientation materials should be co-developed and co-delivered with caregiver advisors. It is advised to have an advisor support orientation<sup>2,5</sup>. Before inviting an advisor to a specific committee, it is recommended they complete the general training<sup>5</sup>.

Orientation and Onboarding practices include the definition and review of:

- Comprehensively Outline their Role, the Project, and Available Supports<sup>1,3-5</sup>
- Administrative Policies, and Paperwork<sup>1,4,5,9</sup>
- Logistical Information and Facility Tour<sup>1,3,4</sup>
- Training in Engagement, Technology, and the Organization's Standard Practices<sup>1,4,5</sup>



## Project/Role Assignment

To forge strong partnerships, guidance in the literature points to the importance of engaging family caregiver advisors in different valued roles throughout an organization<sup>1</sup>, as well as ensuring that the roles/projects offer meaningful, practical value and do not devalue nor frustrate the family caregiver advisors<sup>1,7</sup>. The following list describes a range of activities family advisors can support within an organization:

- Co-Researchers<sup>1,4,5,8</sup>
- Program Co-creators and Evaluators<sup>1,2,4,5,8</sup>
- Advisors on Policy<sup>1,2,4,5,8</sup>
- Assistants with Staff Hiring, Training and Orientation<sup>1,2</sup>
- Educational Curriculum Co-Creators<sup>1,5,8</sup>
- Mentors for other families in working with the agency<sup>1</sup>
- Conference Speakers and Hosts<sup>2,4,8</sup>

For any given position, it is important that the role is clearly defined with the collaborative goal and priorities in mind<sup>1,3,9,13,14</sup>. Determine boundaries, expectations, level of involvement, years of commitment, and accountability for all partners in a 'code of practice' to ensure all team members have the same expectations<sup>1,3,9,13,14</sup>.

To ensure these roles feel fulfilling and non-frustrating for Family Caregiver Advisors, Community Agency and Organizational should:

- Ensure advisor time is well used, focusing only on features that are able to change by their input<sup>5</sup>
- Present sufficient briefings and information on the project background to get everyone involved<sup>4,5,9</sup>
- Use clear, timely, and consistent communication through a variety of means (verbal, written, etc.), even during lulls of activity<sup>1,4,9,13</sup>
- Determine how to track and define success with specific and tangible outcomes<sup>1,3,5,13,14</sup>
- Be transparent and responsible for quality-related issues, expectations, and limitations of influence the council has<sup>5,8,9,14</sup>

## Feedback and Reviews

Figure 1 on page 5, illustrates the link between this lifecycle phase and the previous one of role(s) and assignment(s). The connection between both can be viewed as an ongoing, evolving and iterative dynamic of interaction with the organization and various stakeholders as the family caregiver advisor serves in and transitions from one role(s)/assignment(s) to another. An example of this dynamic is demonstrated through this organization's guidance to provide

participants with new opportunities as advisors once a project has been completed in order to sustain their interest, maintain their engagement and collaboration on future projects<sup>9</sup>. Thus family caregiver advisor's experience is supported and bolstered through continuous feedback/review loops throughout the lifespan their relationship and engagement with an organization. The dynamic serves family caregiver advisors through meaningful feedback and encouragement and the organization through collaborations that create value and meet expectations. To support these exchanges, researched organizations were found to conduct ongoing check-ins with Advisors, gain insight from Advisors through feedback surveys and relay contributions through committee engagement and project reports<sup>1,4,5,13</sup>.

## Exit

Current resources make little mention of exit practices for family caregiver advisors following a role served and/or project completed. It is the researcher's opinion that conducting exit surveys with former family caregiver advisors would prove to be valuable in highlighting continuous improvement opportunities through the lifecycle and span of an organization's relationship with family caregiver advisors to strengthen relationships, sustain engagement and ensure a positive experience.

## Supporting Functions

### Ethic of Care

To successfully integrate family caregiver advisors, the research literature highlights the importance of senior leaders being the ones to lead family caregiver advisor engagement through commitment, promotion, and action<sup>1-4,7</sup>. They must orient the organization around collaborative values, practices, and dynamics, through their long term support and investment<sup>1,4,5,9</sup> and focus on establishing a welcoming environment beyond physical structures<sup>1,2,13,14</sup>; starting first with educating staff on the benefits of engaging family caregiver advisors<sup>1</sup>.

### Values

Actions – and related policies – should reflect the chosen service provider’s values in the commitment charter in engaging family caregiver advisors. Many of the guides advised for service providers to create a list of values. Examples of Service Provider Guiding Principles when Working with Caregiver Advisors:

- Respect<sup>1,2,4,8</sup>
- Compassion<sup>1</sup>
- Empathy<sup>1,4</sup>
- Equity<sup>1</sup>
- Equality<sup>9</sup>
- Active Listening<sup>1</sup>
- Responsiveness<sup>1,2,4</sup>
- Inclusion<sup>1</sup>
- Collaboration<sup>1,4,8</sup>
- Open-mindedness<sup>2,5,9,13</sup>
- Flexibility<sup>13</sup>
- Honesty<sup>2,4</sup>
- Appreciation<sup>2</sup>
- Partnership<sup>2</sup>
- Empowerment<sup>2</sup>
- Transparency<sup>2,5,8,14</sup>
- Understanding<sup>4</sup>
- Accessible<sup>4</sup>
- Dignity<sup>8</sup>
- Participation<sup>8</sup>
- Expecting to Learn<sup>2</sup>

While each organization is unique in their family caregiver engagement<sup>1,2,4,9</sup>, generally organization staff and senior leaders:

- Value family caregiver advisors as essential, equals, and experts from their experiences<sup>1,4,5,13</sup>
- Address language differences and change language to reflect equal partnerships<sup>1,4,5,13</sup>
- Allow for a culture of trial and not a culture of blame or labelling<sup>4,13</sup>
- Frame discussions around system breakdowns and not individual’s mistakes<sup>5</sup>
- Promote a continuous quality improvement culture<sup>2</sup>

## Practical Steps

Additional actions service providers take to equip staff and the organization for meaningful, quality and impactful caregiver advisor engagement include:

- Selectively Hire Staff that Support and can Lead Caregiver Engagement<sup>1,3-5</sup>
- Provide consistent training, education, and mentorship for all stakeholders<sup>1,5,13,14</sup>
- Provide policies, resources, structure, opportunities, and tools for family caregiver engagement without controlling the project's agenda<sup>1,3-5,7,8,13,14</sup>
- Reinforce expectations by reprimanding improper attitudes while celebrating proper involvement<sup>5,11,13</sup>

As well, when dealing with individual family caregiver advisors directly, organization leaders and staff:

- a. Kindly and actively listen to family caregiver advisors<sup>4,13</sup>
- b. Are mindful of the emotion and feelings behind their words and be present<sup>9,13</sup>
- c. Consistently check-in with the family caregiver advisor to build trust and openness<sup>13</sup>
- d. Are responsive to what is shared<sup>13</sup>
- e. Are aware that some family caregiver advisors will need more support than others<sup>4</sup>
- f. Expect that family caregiver advisors will not be able to attend all meetings<sup>4</sup>
- g. Keep family caregiver advisors that miss meetings up-to-date and make them feel valued<sup>4</sup>
- h. Ask for and use suggestions for improvement<sup>5</sup>

## Barriers of Collaborative Efforts with Caregiver Advisors for Service Providers:

When examining the current barriers of collaboration for service providers, the most common limitations can be related to ethics of care. The following barriers to meaningful family caregiver advisor engagement are highlighted in the literature:

- Lack of commitment<sup>5,12,14</sup>
- Additional difficulties with scope and planning<sup>5,11,12,14</sup>
- Lack of Resources for additional costs or staff<sup>2,5,11,13,14</sup>
- Difficulties with team dynamics<sup>5,11,14</sup>
- Lack of support from organization or policy level support<sup>5,12,14</sup>
- Process complications that limit collaboration<sup>5,12,14</sup>
- Current organization's staff and/client culture<sup>1,5,11,12,14</sup>

## Feedback and Appreciation

Recognition for contributions made is important to family caregiver advisors. The literature highlights organization efforts to:

- a. Produce reports connecting family caregiver advisor engagement to impacts and results to reinforce the value and importance of family caregiver advisor contributions<sup>13</sup>
- b. Celebrate success by ‘thank you’s, small gifts, and acknowledgements<sup>3,5</sup>
- c. Ensure offerings (e.g. food, recognition) is culturally appropriate and inclusive<sup>7</sup>
- d. Advertise family caregiver advisory council accomplishments through communication networks internally and externally<sup>7</sup>
- e. Recognizing staff that are engaging with family caregiver advisors appropriately<sup>13</sup>
- f. Acknowledge caregiver advisor contributions and their impact<sup>1,4,5,9,13</sup>
- g. Discuss and address participation barriers <sup>1,5,7,13</sup>
- h.

## Ongoing Training

The literature values providing ongoing training to develop new skills / knowledge through workshops, educational sessions, online modules <sup>1,4,5,9</sup>. They also note that is important to announce future training opportunities for ongoing training and support <sup>1,4,5</sup>.

## Conflict Management

Difference in opinions are expected to happen and, sometimes, these differences may lead to conflict. Before conflict arises, some organizations have anticipated and determined appropriate response methods to address potential situations<sup>1,9</sup>. Organizations are expected to commit to effectively communication and work through differences or conflicts with family caregiver advisors<sup>1</sup>. Some suggested practices include:

- a. Respectfully offering family caregiver advisors, or the staff member, a break from their position<sup>4,9</sup>
- b. Using internal resources and processes to manage the situation<sup>4</sup>
- c. Openly discussing a harmful experience with everyone involved<sup>4</sup>
- d. Using a external facilitator to overcome power differences<sup>5,14</sup>
- e. Enlisting a subcommittee or another group to review and make decisions<sup>5</sup>
- f. Delaying a decision<sup>5</sup>
- g. If there is a problem with performing the duties, address why they are struggling<sup>5</sup>

## Mental Health

### Unique for Mental Health

Although we were able to collect information from some mental health sources, many of the recommendations and noted barriers were not different from those reported in general healthcare settings. From the international review, which intentionally compared mental health programs compared to other chronic illnesses, some uniquely mental health barriers were noted:

- Difficult to engage young men on mental health awareness<sup>14</sup>
- Stigma<sup>14</sup>
- Illness and stress which can result in a relapse<sup>14</sup>
- Faith-based leaders view on mental illness and stigma differed significantly from researchers<sup>14</sup>

## Conclusions

Most of the resources and publication used comprehensively cover similar topics and make similar recommendations; however, there are some gaps in the literature, such as recommendations on family caregiver advisor exits and project matching. For the interests of this study, focusing on mental health stigma and other unique aspects of caregivers in the mental health field will provide novel perspectives and may highly unique priorities important for the knowledge product creation.

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