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Mental Health Commission of Canada

Commission de la santé mentale du Canada

Engaging Caregivers in Mental Health and Addiction Services in Canada

Promising Practices Guide

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- **Cora Cole**, M.Sc., CEO, GreyLit
- **Andrea Bishop**, PhD, GreyLit
- **Lori Wozney**, PhD, Health Outcomes Scientist, Nova Scotia Health Authority; Research Associate, IWK Health Centre

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This guide was conceived and finalized by the MHCC's Knowledge Exchange Centre team:

- **Bonita Varga**, MA, Program Manager
- **Brandon Hey**, MA, Research and Policy Analyst
- **Alexa Bol**, MA, Knowledge Broker
- **Francine Knoops**, A/Manager, Policy and Research

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Introduction

Undeniably, caregivers play an important role in the recovery journey of people living with mental health and addiction (MHA) problems and illnesses. Yet, their voices and needs remain overlooked in many parts of the MHA system in Canada. As few as 34 per cent of organizations include clients in quality improvement (QI) initiatives or in the design of health-care services, and they collect little to no data on family caregiver engagement in QI.[1] However, there are encouraging signs that health-care organizations throughout Canada are beginning to pay closer attention to family caregiver engagement in the design and delivery of health services.

For most of the one in five Canadians who experience a mental health problem or illness in any given year, at least one family caregiver provides support. Within health care, these caregivers provide 75 to 80 per cent of all client care.[2, 3]

But family caregivers need adequate support to sustain their role.[4] As many as 50 per cent perceive their role as negatively affecting their own mental health.[5] Historically, family caregivers felt they were being blamed for their loved one's MHA problems and illnesses. While that is no longer so, caregivers are not consistently recognized as potential partners in their loved one's recovery journey, nor as needing support to maintain their own well-being. Many still feel marginalized and carry heavy burdens, which are reflected in a combination of social, economic, and health-related costs.[6, 7, 8]

In 2013, the Mental Health Commission of Canada's (MHCC's) National Guidelines for a Comprehensive Service System to Support Caregivers of Adults Living with Mental Health Problems and Illnesses (Caregiver Guidelines) served as a roadmap for engaging and meeting the needs of caregivers across the continuum of care. Since then, the MHCC has met with Canadian champions of family caregiver engagement on numerous occasions to explore opportunities to further advance these guidelines. There was broad agreement that one priority is to share information about good practices in a way that can inspire and guide organizations in engaging caregivers.

The purpose of this Promising Practices Guide is to furnish MHA organizations with key considerations for family caregiver engagement, based on the best available evidence, and provide examples of good family engagement in care, programs, and policies.

The Case for Caregiver Engagement

Policy

Many provinces and territories have identified client-centred care and recovery-oriented practice as keys to improving MHA systems.[9] Actively engaging service users by involving them in matters that affect them, such as treatment planning, systems planning, and governance, can help situate service providers and service users on a more level playing field.[10, 11] Internationally, countries like Australia and the U.K. are increasingly adopting policies, standards, and practice guides to strengthen family caregiver involvement in mental health service delivery, planning, and evaluation.[12, 13] One example of a practice guide is the Triangle of Care (Figure 5),[14] used by Carers Trust as a basis for mandatory staff training to support caregivers in England, Wales, and Scotland. Family caregiver involvement policies in the U.K. and Australia grew out of an initial focus on client engagement and a recognition that the experience of caregivers and clients is inextricably linked.[15, 16]

In Canada, provinces and territories are increasingly following suit. A number of provincial and territorial (PT) mental health and addiction strategies and action plans call for meaningful family caregiver involvement across all levels of care. Most PT plans commit to providing better psychosocial supports for family caregivers and to sharing information related to a loved one's illness and recovery.[17]

As with client engagement, family caregiver engagement is one aspect of achieving the Institute for Healthcare Improvement's Triple Aim, which includes improving the individual experience of care and the health of populations while reducing health-care costs.[18, 19, 20] Many aspects of these aims are realized by improving patient safety, client satisfaction, treatment retention, and making systems of care more relevant and friendly* to those who receive it.[21, 22]

Recovery

Engaging caregivers facilitates and expedites pathways to recovery for people living with MHA problems and illnesses. Caregivers provide the emotional, social, and material support these people need to improve their quality of life.[23, 24, 25, 26] Since so much of a person's recovery journey occurs outside the mental health system, to foster recovery we must understand people within the context of their own lives.[27] Caregivers contribute most to a loved one's recovery when their involvement is welcomed and their experience is acknowledged.

* For these reasons, client-family experience, inclusion, and participation are key domains of a forthcoming (spring 2020) MHCC report that frames quality collaborative care, called *Advancing Collaborative Mental Health Care in Canada's Primary Care Settings: A National Quality Framework with Recommended Measures*, authored by Sunderji, et al.

The MHCC's Guidelines for Recovery-Oriented Practice emphasizes the value of family, friends, and the community to a person's recovery journey. It provides clear recommendations for the kinds of values, attitudes, knowledge, skills, and behaviours that enable providers to effectively engage caregivers (see Appendix D). As important as those elements are, it's impossible to talk about a recovery-oriented system of care without acknowledging the importance of the caregivers' role.

> In this guide, we define caregivers as family, friends, co-workers, neighbours, or anyone who is in a supportive role for an adult with mental health, substance use, or addiction problems or illnesses.

The Value of Caregivers

Despite their crucial role in supporting the mental health of loved ones, the practical, social, emotional, informational, and financial support caregivers provide remains undervalued. Managers in mental health, addictions, and psychosis treatment can still have unsupportive attitudes toward family caregivers and their engagement.[28] Yet, within health care, these caregivers save the Canadian economy an estimated $25 billion annually.[29] The unpaid care and support family caregivers provide represents a major contribution to our health and social service systems, and replacing that care and support with formal services would be very costly.[30] If, instead, we enhanced family caregiver engagement, we would

- improve the health of clients and their families[31]
- reduce our reliance on health services[32]
- create more meaningful partnerships in systems of care[33] and increase staff members' satisfaction with their career choices[34]
- enhance the mental health system's responsiveness to family and community needs[35, 36]
- improve caregivers' confidence and competence in their role[37]
- help family caregivers participate more fully in continuous quality improvement and enhance the relevance and impact of systems of care[38, 39]
- help normalize and spread the practice of family caregiver engagement across the health system.[40]

Overview of this Guide

This *Promising Practices Guide* seeks to support MHA services in planning and carrying out meaningful engagement with caregivers. A literature review, environmental scan, policy scan, and pan-Canadian roundtable showed that more information on good practices for family caregiver engagement was needed. The growing emphasis on such engagement – in policy and accreditation standards – shows that organizations and practitioners are looking for clear, succinct guidance on what to do and how to do it.

The guide was developed with input from community organizations and caregivers with lived experience. Their focus was to ensure that it offers practical advice for the MHA services, agencies, and organizations that wish to implement or strengthen family caregiver engagement in policy, planning, and care delivery.

In brief, this *Promising Practices Guide*

- summarizes the existing literature on what works to meaningfully engage caregivers across the continuum of health service delivery
- highlights promising practices and potential barriers to implementation
- informs stakeholders about any gaps in evidence
- promotes the organizational or local community mapping of untapped or existing caregiver resources
- profiles promising Canadian programs, services, and policy initiatives that promote caregiver engagement at the organizational level
- supports mental health and addiction organizations' efforts to promote the value of engaging caregivers and to improve caregivers' experience with MHAs and the care of their loved ones.

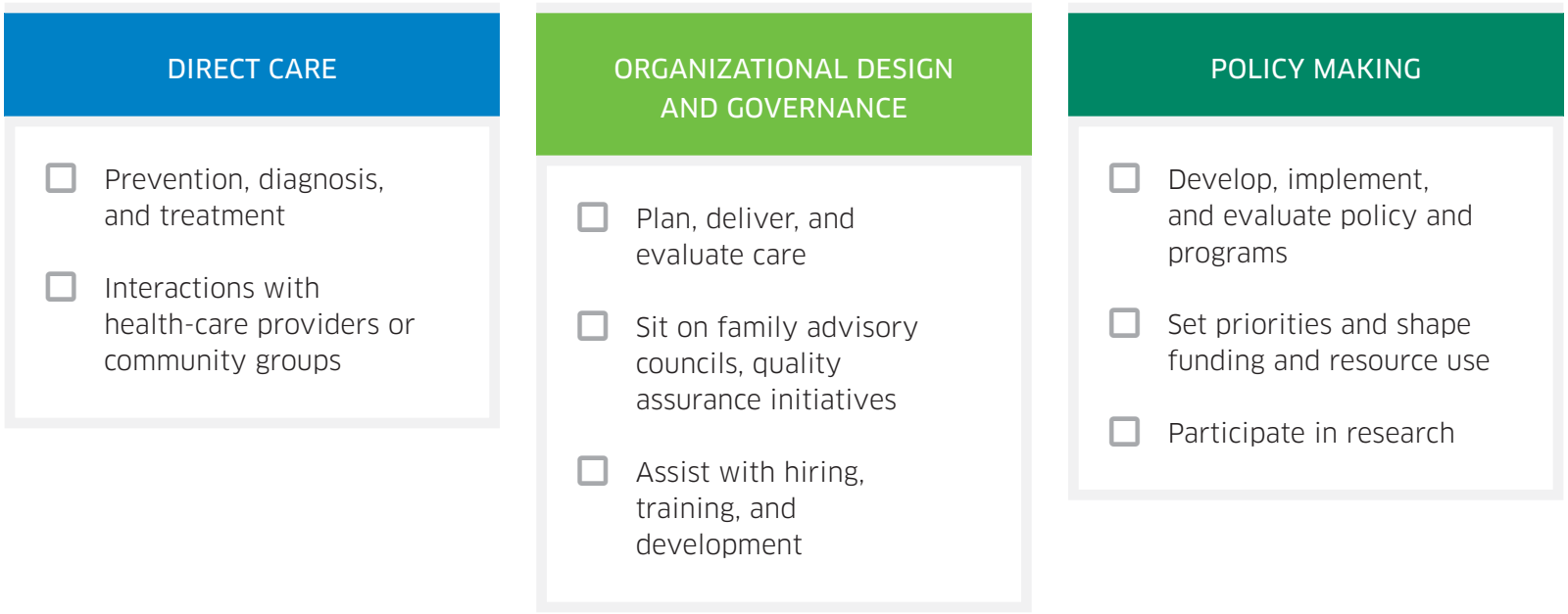
Engaging Caregivers Well

Where and How

The increased focus on client-centred care, where engagement is foundational, has led to a parallel increase in attention to caregiver engagement in cancer,[41] dementia,[42, 43] and palliative care.[44] While this literature continues to grow, a few evidence-based engagement tools and frameworks are now available to assist MHA organizations when considering where and how to engage caregivers.

Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies[45] recommends that organizations think about how they engage caregivers at three levels: (1) direct care, (2) organizational design and governance, and (3) policy making (as represented in Figure 1).

FIGURE 1. – WHERE TO ENGAGE CAREGIVERS



Because caregivers can provide MHA organizations with a lived-experience perspective where and when it is needed, they should engage them across all three levels. For example, if an organization wishes to establish a new family ombudsman position, it would be appropriate to engage caregivers at the second and third levels. If it wants to implement a new care planning policy, they should engage caregivers at all three levels. Taking the time to understand the impact of the caregiver voice at each of these levels will help organizations plan their caregiver engagement strategy (as represented in Figure 2).

FIGURE 2. – IMPACT OF CAREGIVER VOICE ACROSS THE THREE LEVELS

Once an organization determines the broad goal and scope for its strategy, it should decide how it will engage caregivers. Engagement can occur along a continuum and will be specific to each activity and caregiver. The International Association for Public Participation's (IAP2's) Spectrum of Public Participation (Figure 3) is a useful way* to consider how to engage caregivers and what level of engagement is most appropriate for your organization and its community.[46] These levels may range from informing caregivers of an upcoming change in service delivery to involving their participation in meetings, policy development, and implementation planning.

Many factors will influence how an organization engages caregivers. An organization's efforts could, for example, be affected by caregivers who don't want to become engaged or can't spare the time. A caregiver's health literacy or health status could also be barriers to engaging them. Whichever strategies are used, it is best to work closely with caregivers, understand their day-to-day lives, and provide engagement opportunities that meet them "where they're at." Engaging caregivers should not add to their burdens, and the experience should meet the needs of both parties.

FIGURE 3. – IAP2 SPECTRUM OF PUBLIC PARTICIPATION

* IAP2's tools can be useful when starting to plan caregiver engagement. Appendix A includes a list of other resources that may be of help along the way.

Review and Scan Findings

The review of the international evidence on engaging caregivers in mental health and addiction services (see Appendix B) undertaken for this report builds on the literature review in the MHCC's *Caregiver Guidelines*. The new review identified 15 relevant reports, systematic reviews, and research articles (published between 2015 and 2018). Most of the available evidence originated in the U.K. and Australia.

We also undertook a scan of caregiver engagement in Canada to find examples of promising practices through a public call (Nov. 12 to Dec. 19, 2018) to MHCC key contacts, which resulted in 55 submissions. The MHCC team categorized these responses based on region, organization size, level of caregiver engagement, degree of co-design, language availability, and populations served (e.g., serious and persistent mental illness; substance use; adults, children, and youth; Indigenous; immigrant, refugee, ethnocultural, and racialized communities; LGBTQ+). A small set of eight examples were selected as case studies for this guide. These reflect a diverse range of exemplary practices in Canada's MHA system. They also shed light on where further research is needed to fill gaps in the currently available evidence. (see Table 1 and Appendix C).

We asked each of the eight organizations to provide details about their origins and operating context and to share insights about the key ingredients of success and the lessons learned about good engagement. Across these examples, success was based on some combination of four elements:

True power sharing with caregivers

Using co-design, partnership, and peer-led initiatives

Developing proficiency

Organization-wide cross-training (i.e., "integrating into the hospital milieu"), capacity building, or knowledge translation mechanisms across diverse health-care and caregiver groups (e.g., "train the trainer" models)

Organizational readiness to family caregiver engagement

Realized via its commitments to client–and family–centred care, an acknowledgement of caregiver expertise, and quality improvement efforts (through adhering to accreditation standards)

Flexing organizational policies

Focusing on health equity and on being flexible about how and when to involve caregivers through dynamic hours, technology, and creating safe spaces

Table 1 provides an overview of each promising practice case study. Appendix C provides more detail about each program and their journeys.

TABLE 1. – CASE STUDIES OF PROMISING PRACTICES: OVERVIEW

CASE STUDY	DESCRIPTION	IMPLEMENTATION CONSIDERATIONS	BENEFITS AND OUTCOMES
1. Canadian Mental Health Association (PEI) Family Caregiver Program	CMHA-backed peer-supported and peer-led caregiver program	Programs in big cities operate differently than those in PEI: rural areas can have fewer volunteers and more stigma	Strengthened relationships with other organizations, family peer support now a formal program
2. Cornwall Hospital Embrace Program (Ontario)	A hospital-wide strategy to include caregivers as equal partners in care, created with a Cornwall District family support group	Identify and leverage champions with the "clout" and clear messaging to make changes happen	Caregivers feel their contributions are valued and they are participating in a collaborative and inclusive culture change
3. Centre for Addiction and Mental Health Office of Family Engagement (Ontario)	Following a strategic review, recognized the need to improve support, increase voice of caregivers through co-design and creation of an office for family caregivers	Need to continuously work across the organization through co-design principles, share learnings across departments and people involved	Commitment to family caregivers improved client-family experiences and outcomes
4. Families Supporting Adults with Mental Illness in Alberta	Peer-focused family caregiver support group supported by CMHA Edmonton, from grass-roots advocacy by parents frustrated by the mental health system	Need to use resources to build capacity across groups, share learning, and overcome tension between research and grassroots needs	Increased referrals Now endorsed and supported by city counsellors and health service organizations

CASE STUDY	DESCRIPTION	IMPLEMENTATION CONSIDERATIONS	BENEFITS AND OUTCOMES
5. B.C. Schizophrenia Society (BCSS) and BCSS Prince George Branch's F.A.M.I.L.I.E.S. Peer Specialists and F.A.M.I.L.I.E.S. in Residence	Nationally accredited family peer support program linked to national standards of practice that oversees project planning, generates reports, integral to quality improvement	Need to balance competing priorities and resistance to change	Increased awareness of family caregiver needs and knowledge of available family peer-support services
6. AMI-Quebec – Family Peer Support in Emergency Rooms	Program to provide better, more formalized family peer-support services in Montreal-area emergency rooms	Need dedicated caregiver positions, shift impetus from care for clients only to care for caregivers too; tie culture change to hospital's own goals	Reached more people earlier in their own and loved one's recovery journey, reducing and alleviating caregiver burden
7. ACCESS Open Minds – Family and Carers Council (National)	Initiative to advocate for funding and developing effective and sustainable approaches to family engagement and family peer support	Need to attract leadership and champions in family caregiver engagement with diverse skill sets and experiences; need resources to build capacity across groups	Greater involvement of family caregivers in advisory committees; increased commitment among researchers to involve clients and family caregivers in mental health research
8. Making Family Engagement and Family Peer Support a Reality in Early Intervention Programs for Psychosis in Quebec – A CIHR-SPOR Collaboration Grant Project	Project to improve services and family caregiver supports in first-episode psychosis through consensus- development process and capacity-building opportunities	Need to get enough interest across diverse stakeholders, with enough money, time, effort to plan, implement, and sustain changes	Caregivers empowered to change clinical programs (community of practice and knowledge transfer were key to making changes and realizing recovery principles)

Four Key Ingredients of Success

Four key ingredients for successful caregiver engagement emerged from the evidence review and the eight case studies:

1. Engage caregivers at the outset.
2. Foster shared expectations and accountability.
3. Take a flexible, strengths-based approach.
4. Create a planned and supportive process of engagement.

1. ENGAGE CAREGIVERS AT THE OUTSET

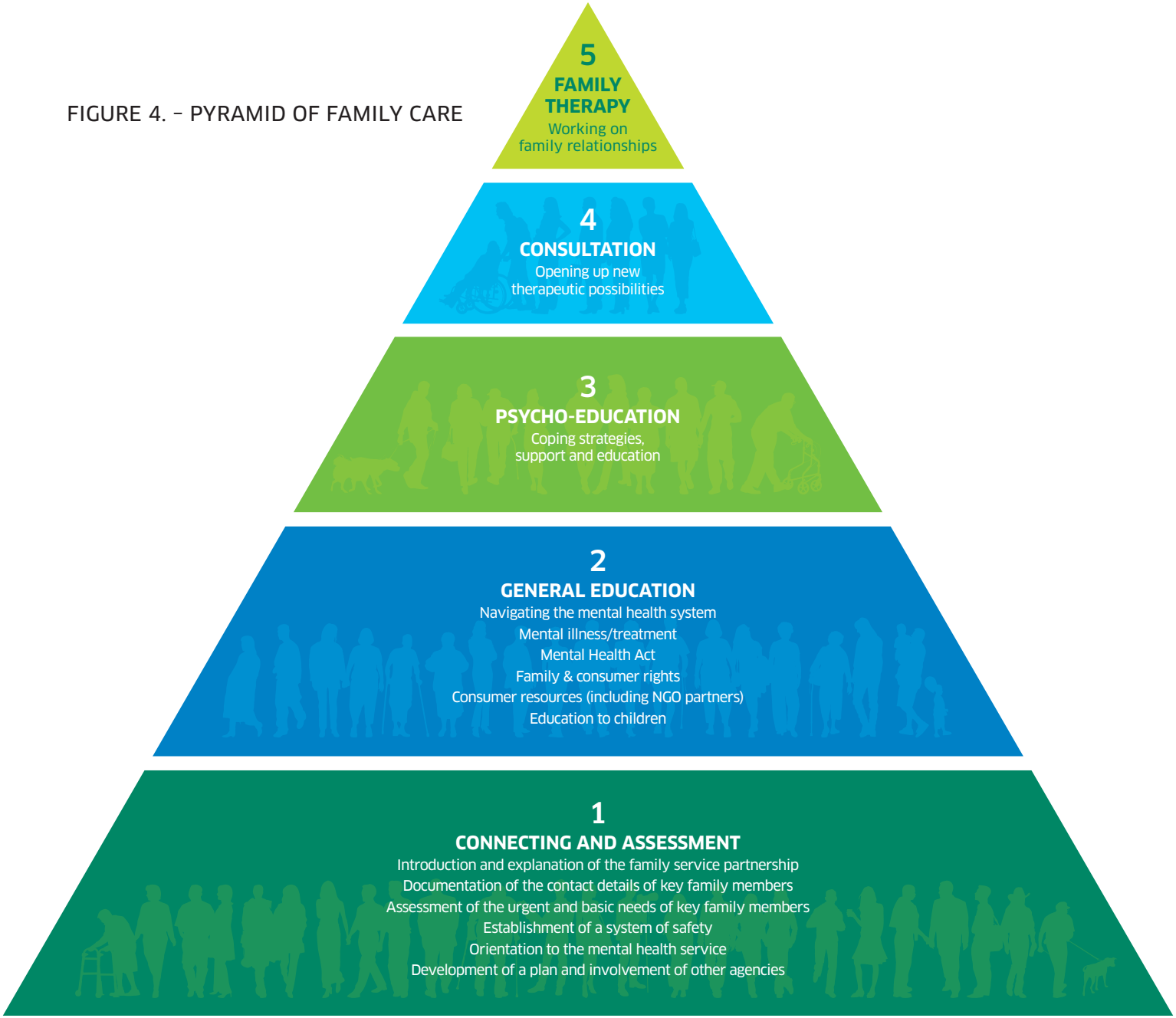
Before initiating new services, programs, or policies, we encourage organizational leaders to connect with caregivers in their communities. The caregivers you contact can either be engaged as part of the initial priority-setting process or as long-term advisers. Regardless, they need to be valued and recognized as partners in care from the onset – whether in direct care, program development, or policy making.

Apart from starting early, caregiver engagement must be ongoing. Getting feedback after decisions are made cannot replace engagement before and during a priority setting and development process. Hearing caregivers' concerns and expectations, and what can improve their engagement or care experience throughout the process generally, produces better outcomes. After a program or initiative is set up, it is also good practice to periodically review the makeup of working groups, advisory boards, and evaluation teams, and evaluate initiatives, policies, practice guidelines, and specific caregiver-engagement efforts.

The Pyramid of Family Care (Figure 4), originally proposed by Mottaghipour and Bickerton in 2005, was used in the *MHCC's Caregiver Guidelines* to frame different task levels for meeting the support needs of family caregivers. It remains a useful tool to help organizations and front-line care providers plan caregiver services and engagement.[47] Levels 1 and 2 reflect the foundational supports all caregivers need. In levels 3, 4, and 5, caregivers are given more intensive supports in relation to coping, providing care, and changing family dynamics as these needs are identified. Engaging caregivers at the foundational level can help identify additional needs so that a caregiver can remain appropriately engaged throughout their loved one's care. The goal is to support caregivers according to their level of need throughout their loved one's recovery journey.

CMHA Peel-Dufferin created a family checklist that was shared through the regional family support program at the Royal Ottawa Hospital. The checklist helps service providers assess the needs of caregivers based on the Pyramid of Care (see Appendix E).

FIGURE 4. – PYRAMID OF FAMILY CARE



Engaging with caregivers

Sometimes it's easy to find caregivers who want to engage with your service or organization and to understand their needs; at other times, it's more challenging. Speaking with caregivers who already use your services is one way to learn how you can better meet these needs. Caregiver advocacy and support organizations can also help you identify, engage, and work well with caregivers. They can be an important resource to your service and a gateway to supports for individual caregivers. The following represent the major pan-Canadian or regional organizations that serve the caregivers of people living with mental health and addiction problems and illnesses:

Pan-Canadian MHA organizations with a caregiver focus:

- Access Open Minds (Youth)
- Alzheimer Society Canada
- Families for Addiction Recovery
- Mood Disorders Society of Canada
- National Initiative on Eating Disorders
- Schizophrenia Society of Canada

Provincial caregiver advocacy organizations:*

- Caregivers Alberta
- Caregivers Nova Scotia
- Family Caregivers of British Columbia
- Ontario Caregiver Organization
- Réseau avant de craquer (Quebec)

PROMISING PRACTICES

"Don't start until you've spoken to families in the area. Success is based on trust and the value peer facilitators bring. They can talk the talk because they've walked the walk."

The Canadian Mental Health Association Prince Edward Island developed its peer caregiver support program over 15 years ago. They have succeeded by welcoming the caregiver voice from start to finish. Using existing best practices and listening to the needs of these caregivers, this family caregiver program balances the evidence and practice of engagement to meet the needs of PEI caregivers. (See Appendix C to learn more.)

* While some of these organizations do not specifically focus on MHA, they provide leadership to strengthen the voices of family caregivers in their respective regions. The may have family advocates or connections across their jurisdictions.

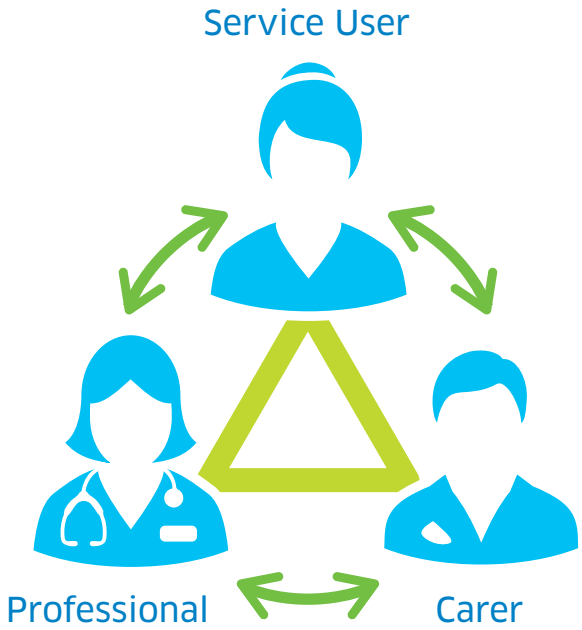
2. FOSTER SHARED EXPECTATIONS AND ACCOUNTABILITY

Formally recognizing caregivers – for example, through legislation, policies, or organizational mandates – is an effective way to acknowledge their value. But paying attention to the implementation process is equally important, especially since organizations face competing priorities and a range of considerations in achieving quality improvement goals. To normalize caregiver engagement and motivate change, developing explicit standards-based accountability structures is helpful. Organizational commitment is unlikely without well-defined expectations and, in turn, clear expectations build trust. Policy implementation tools include making caregiver engagement a strategic priority, creating accountability mechanisms, establishing benchmarks for engagement, and setting expected outcomes or goals to be monitored and evaluated.

Creating a triangle of care

Standards or guidelines that place service users and caregivers at the centre can also be helpful implementation tools. Carers Trust in the U.K. uses the Triangle of Care[48] to frame an expectation of collaborative relationships between providers, caregivers, and service users while tying those relationships to MHA accreditation and policy mandates. This guideline emphasizes a three-way relationship focused on hearing all voices for a successful journey of recovery for the service user.

FIGURE 5. – TRIANGLE OF CARE



3. TAKE A FLEXIBLE, STRENGTHS-BASED APPROACH

Respecting and honouring the strengths of all caregivers in their diverse life contexts, while finding ways to empower them by helping them build their skills and providing the particular supports they need, are key to meaningfully engaging caregivers. Understanding these diverse life contexts, which include such wide-ranging factors as social and economic circumstances, community and culture,

work schedule, literacy skills, etc., helps to identify what may be needed to get a caregiver engaged. Although such needs could mean accommodations, such as offering opportunities outside normal working hours or providing daycare for their children, respecting each caregiver's needs and skills while meeting them "where they're at" can produce many benefits. These include more involved caregivers, a higher quality of engagement, a richer diversity of voices contributing to a service or organization, and stronger collaboration between service users, carers, and service providers.

Organizations seeking to engage caregivers as volunteers beyond the direct care triangle have additional considerations. After defining what they want to achieve when engaging caregivers and what kind of engagement is suitable (based on the IAP2 spectrum in Figure 3), they can explore ways to make the engagement experience work well for diverse stakeholders using a flexible, strengths-based approach. For example, an organization could offer opportunities for collaboration and involvement in policy and program planning process for caregivers with interest, time, and skills in this area. Feedback tools such as online surveys offer busy caregivers one-time engagement opportunities, while ongoing leadership opportunities such as co-chairing an event or a group may be more appealing to others.

PROMISING PRACTICES

"Time was invested to ensure caregivers were comfortable with the communication technology (i.e., Zoom) used by the project team. Team members tested and sent meeting requests through Outlook and ensured caregivers could open files and set up online/video meetings. This gave confidence and levelled the playing field between 'staff' and caregivers."

The Cornwall Hospital's Embrace program is a strategy to include caregivers as equal partners in all aspects of the hospital operations. From the start, Embrace has used a true co-design approach based on four pillars: (1) structure, (2) guidelines, (3) training, and (4) technology. Given the rural location of the hospital, greater support is needed to engage caregivers. Utilizing technology, with adequate training and support has helped to engage them meaningfully and flexibly. (Read more in Appendix C.)

4. CREATE A PLANNED AND SUPPORTIVE PROCESS OF ENGAGEMENT

Caregivers involved in organizational activities, such as shaping policy and programs, thrive best in a supportive context. A supportive process includes mentorship, defined roles and responsibilities, and provisions for meeting financial needs. Articulating the purpose of engaging a caregiver in a particular role and conveying required qualifications or time commitments are fundamental. A planned and supportive process for engagement also means having adequate, sustainable funding and other resources in place. For example, organizations could provide web conferencing software, salary support, and honorariums, or they could cover caregivers' meeting costs or other expenses (e.g., bus tickets, parking, child care, etc.). Continual outreach is essential for maintaining an active and diverse caregiver voice, as is relying on more than just a few caregivers to reduce the risk of burnout.

Compensation for caregiver engagement

Organizations need to plan to ensure that their caregiver engagement is sustainable while honouring, caregiver contributions appropriately. Open and honest discussions between caregivers and health organizations can help identify any "unseen" costs (e.g., travel, parking, child care) of tapping into the skills and knowledge caregivers bring to the table. Budgeting should also include staff costs to support their engagement of family caregivers.

The George and Fay Yee Centre for Healthcare Innovation offers an easy-to-use patient engagement budgeting tool to help organizations uncover some of these costs and budget for engagement activities.

PROMISING PRACTICES

"There is the expectation that caregivers are asked to participate and give time freely, but others at the table are getting paid for their time. Are you paying staff with Tim Hortons gift cards? Is the work they do more important than what caregivers bring?"

The ACCESS Open Minds family and carers council provides support, education, and resources to family and carers. It seeks to foster the engagement, participation, and collaboration of family and carers in all aspects of the program. While funding remains a significant challenge, the value of caregiver engagement has been felt – they are contributors, not just consumers. With the value of caregivers' free health services estimated in the billions of dollars every year, their contribution to the health economy, their time, and effort should be similarly recognized. (See Appendix C to learn more.)

Caregiver Engagement Scoping Activity: Critical Questions

Launching a new program, service, or policy initiative to engage caregivers takes planning. The Promising Practices Case Studies (Appendix C) point to questions organizations could ask themselves when initiating a caregiver engagement program or strategy. The following checklist can be used to identity key questions or resources that are most relevant to a particular setting or planned service.

STAGE 1. BUILDING AWARENESS AND TRUST

- ☐ What opportunities will we create to better understand caregiver needs and experiences?

  Examples (select activities appropriate for your objectives):
  - ☐ hiring family support workers
  - ☐ advisory groups
  - ☐ focus groups
  - ☐ town hall meetings
  - ☐ surveys
  - ☐ check-ins during regularly scheduled appointments
  - ☐ feedback forms
  - ☐ suggestion boxes
  - ☐ other:

- ☐ How will we engage caregivers (at the outset and during direct care) to support their needs?

  Examples (see the Family Checklist in Appendix E for more ideas):
  - ☐ identify their expectations
  - ☐ determine beneficial supports
  - ☐ learn how they would like to be involved in their loved one's care
  - ☐ other:

- ☐ How will we identify and connect with diverse caregivers so that they bring new faces, experiences, and stories to the table? How will we engage them in a culturally appropriate way?

  Identify culturally specific programs or community agencies that you can partner with:
  - ☐ LGBTQ+ organizations
  - ☐ friendship centres
  - ☐ settlement agencies
  - ☐ youth programs for carers
  - ☐ other:

- [ ] How will we engage caregivers in ways that create an environment of hope and optimism?
  - See the *MHCC's Guidelines for Recovery-Oriented Practice* or Appendix D for ideas.
- [ ] What resources and supports are available in our community?
- [ ] How can we stay on top of new research and evidence about what works for caregivers?
- [ ] Are there professional development opportunities available to increase knowledge and capacity?

  Examples:
  - [ ] conferences
  - [ ] webinars
  - [ ] podcasts
  - [ ] training with caregivers
  - [ ] other:

STAGE 2. CONFIRMING COMMITMENT TO CHANGE

- [ ] Do decision makers support the hiring of caregivers as paid staff?
- [ ] Are resources available for caregivers to share their stories of success to help improve services?
- [ ] How will executive leaders encourage and champion better caregiver engagement?
- [ ] How much time (meetings, webinars, in-person events, or strategic planning sessions) are staff and caregivers expected or able to dedicate?
- [ ] What resources (human, in-kind, and cash) can be dedicated to implementing and sustaining meaningful engagement?

STAGE 3. REAL-WORLD IMPLEMENTATION

- ☐ Do we have a plan to implement our engagement initiative?
  - The MHCC's innovation to implementation guide is a helpful tool for moving an idea into a plan.
- ☐ How will we monitor and evaluate progress and celebrate caregivers' successes?
  - The RE-AIM Framework and the Kirkpatrick model are evidence-based evaluation tools with free, online materials.
- ☐ Who is accountable for setting objectives? How will we ensure transparency with caregivers?
- ☐ What is the sustainability plan for this initiative?

Where Do We Go from Here?

The review of the literature, together with the Promising Practices Case Studies (Appendix C), have identified areas where gaps remain. These evidence and knowledge translation gaps include the following:

ORGANIZATIONAL OPERATIONS

Caregiver engagement can be resource intensive. Most organizations get around this by providing in-kind support (external and internal) rather than dedicated funding. Details about the cost of engagement initiatives, including staff time, training or onboarding, payment for caregivers, and translation services, could be more readily shared. Doing so would help others evaluate their return on investment and better understand the resources they need to undertake this work.

FAMILIARIZING PROVIDERS AND CAREGIVERS

While educating providers about caregiver needs and engagement makes it more likely that caregivers are treated as equal partners in care, more research is still needed on how best to educate providers about caregivers' needs (e.g., formal training, peers) or how to "train-up" or cross-train caregivers with service providers in the area of policy and program planning. Since family peer-support credentials link to national standards, curriculum-based training may be important avenues for exploration and growth.

Research on anti-stigma initiatives also shows that social contact from a trained speaker with lived experience is an effective way to change attitudes, behaviours, and beliefs.[49]

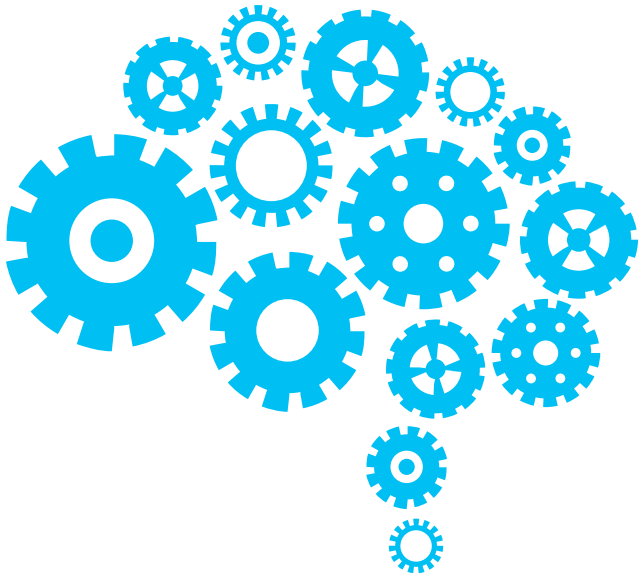
CAREGIVER DIVERSITY

For many reasons it's not always easy to get caregivers from diverse backgrounds to the table. As a result, Indigenous, immigrant, refugee, ethnocultural, racialized, LGBTQ+, and young caregivers are often left out of the conversation. Greater understanding of how to engage a diversity of caregivers is needed, which may require different supports and engagement approaches. Organizations may benefit from working in partnership with organizations that serve these populations in other capacities, like settlement agencies or friendship centres. While there are many common caregiver experiences, there may also be unique cultural, community-based, or mental-illness and addictions-specific experiences that generic supports do not capture. Entering dialogues from a place of cultural humility is a good place to start. Knowing the demographics that do or don't exist within your caregiver community is critical to an engagement program's success. Taking the time and making the necessary investment to work with diverse stakeholders will inevitably improve services.

ADDICTIONS-FOCUSED CAREGIVER EXPERIENCES

While this guide examines both mental health and addiction services, we know that families experiencing addiction have unique challenges. Engaging them in policy and program planning may require tailored solutions or approaches. We need more information about such challenges to generate best practices in this area.

> "Try not to reinvent the wheel. Ask for help and resources. There are so many examples of great, creative-engagement work that hospitals and other organizations are doing."
>
> – CAMH Toronto



Appendix A

Caregiver Engagement Resources

CANADIAN FOUNDATION FOR HEALTHCARE IMPROVEMENT

Patient Engagement Resource Hub

CENTRE OF EXCELLENCE ON PARTNERSHIP WITH PATIENTS AND THE PUBLIC

CENTRE FOR HEALTHCARE INNOVATION

CHANGE FOUNDATION

Family Caregivers

INSTITUTE FOR PATIENT- AND FAMILY-CENTRED CARE

Better Together: Partnering with Families

PEER SUPPORT CANADA

ACCREDITATION CANADA AND HEALTH STANDARDS ORGANIZATION

Leading Practices Library

Engaging Indigenous Caregivers

ONTARIO CENTRE OF EXCELLENCE FOR CHILD AND YOUTH MENTAL HEALTH

Resource Hub

THUNDERBIRD PARTNERSHIP FOUNDATION

Family Members/Caregiver Guidebook (Document Library)

Appendix B

Literature Synthesis

1. METHODS

The search strategy for the rapid scan was developed in consultation with the Maritime SPOR (Strategy for Patent Oriented Research) support unit's evidence-synthesis expert and a GreyLit health librarian. The academic review included searches of five relevant databases: MEDLINE, Embase, PsycINFO, CINAHL, and Scopus. Search terms, which were approved by the MHCC, included combinations of population (e.g., caregiver, carer, family); service (e.g., mental health, addictions, service delivery); and intended outcomes (e.g., engagement, participation, empowerment) key terms. Terms were developed for MEDLINE (Table 2) and translated across the other four databases.

TABLE 2. MEDLINE KEY TERMS

1. ((caregiver* or care giver* or carer*) adj2 (engage* or involve* or activat* or participat* or empower* or collaborat* or decision*)). ti,ab.
2. ((family or families or relative or relatives) adj2 (engage* or involve* or activat* or participat* or empower* or collaborat* or decision*)).ti,ab.
3. ((partner or partners or spouse* or husband* or wife or wives or loved one*) adj2 (engage* or involve* or activat* or participat* or empower* or collaborat* or decision*)).ti,ab.
4. or/1-3
5. exp Mental Disorders/
6. Mental Health/
7. exp Mental Health Services/
8. ((mental* or psychiatr* or psycholog*) adj2 (health* or disease* or disorder* or ill or illness* or patient* or problem*)). ti,ab.
9. addict*.ti,ab.
10. alcoholi*.ti,ab.
11. ((alcohol or drug* or substance*) adj2 (abuse* or depend* or disorder* or habit* or "use" or user* or using)).ti,ab.
12. (amphetamine* or cannabis or cocaine or heroin or marijuana or meth or opioid*). ti, ab.
13. or/5-12
14. 4 and 13

Reports were not excluded based on their method or design but were excluded if they (1) dealt only with pediatric client populations, (2) focused on family treatment or co-therapy approaches, (3) focused on identifying caregiver needs generally, (4) discussed engagement of caregivers in academic research only, or (5) reported on caregivers of persons with dementia. Studies published from January 1, 2015, to the present were included. The academic literature search was performed on October 1, 2018.

A grey literature search was carried out (by a library scientist) to identify governmental and organizational reports for caregiver engagement in adult mental health. Date limits were not imposed in the hope that a "landmark" report existed. The search was performed on October 21, 2018, and included grey literature repositories throughout North America, the U.K., and English resources in Europe. A total of 15 reports were identified.

The selection of studies involved a two-phase screening process. After removing duplicates, 3,463 report abstracts were imported into systematic-review software (Covidence). Two team members screened the titles and abstracts, and the relevant studies were reviewed fully and independently by both team members. Discrepancies were resolved by means of discussion. Ten academic studies and five grey literature reports were identified and reviewed. The data-extraction form was revised in consultation with the MHCC to promote consistent and reliable extraction around key indicators. The data-extraction form was piloted using three studies and refined to ensure that all necessary data was captured.

2. SUMMARY OF FINDINGS

The majority of the studies/reports (60 per cent; 9/15) were from the U.K., with the remaining coming from Australia (27 per cent), Canada (13 per cent), and the Netherlands (one). Three studies were systematic reviews of the existing literature, and the remaining twelve studies/reports were either primary studies, program evaluations, or descriptive accounts. Most documents reported on the engagement of caregivers in new service design and delivery (11/15; 73 per cent). Half focused on engaging caregivers in improved care planning (8/15; 53 per cent). The studies/reports referenced broad community mental health service contexts (rural and urban combined) and did not differentiate between mental health and addiction services. None of the reports focused on stigmatized or culturally unique client or caregiver populations (e.g., First Nations communities, sibling caregivers). Detailed demographic information on the caregivers involved in these programs or interventions were rarely reported; therefore, we cannot say who (parent, spouse, sibling, friend) was the primary target of the proposed practices.

The training of caregivers was reported in 33 per cent (5/15) of the studies/reports. Only two identified compensation and remuneration structures for the caregivers involved. The evaluative component of the studies/reports was very limited: the evidence was typically thematic in nature, and many reports on caregiver engagement did not have quantitative evidence of impact. Where evidence was provided, it focused largely on acceptability/satisfaction measures (i.e., whether caregivers liked or valued the service), not on client outcomes (i.e., whether involving caregivers resulted in improved functioning or quality of life). One of the largest studies[50] found no significant impact from embedded decision-making involving caregivers on outcomes.

Most reviews and reports cited a lack of research on the impact of caregiver engagement on client outcomes and health-service use. Of note is that this is not unique to the mental health service field. It has been mentioned in a number of medical domains in which caregivers play a key role.

Appendix C

Promising Practices Case Studies

Eight organizations were asked to participate in an interview that describes how their organization is engaging caregivers at the program, policy, or strategy level. Following the interviews, organizations reviewed their responses and validated interpretations, so that it aligned with their experiences. Every effort was made to ensure the case study findings carefully reflected caregiver voices and perspectives. Consequently, caregivers are referred to as family, caregivers, and carers.

Case Study

1.

Canadian Mental Health Association (PEI) Family Caregiver Program

OVERVIEW

The Canadian Mental Health Association (CMHA) in PEI has been offering support to caregivers for more than 15 years through their family caregiver program. Two years ago, the program was re-designed to become more peer led. Peer facilitators with experience as a caregiver of an individual with mental illnesses or problems and/or addiction now co-design and develop content. They are also directly involved in implementing the program.

This is an eight-week program that runs two hours per week to help family caregivers find the supports they need. It also helps them gain new skills and learn about good practices in supporting a loved one on their mental health and addictions journey. The program is for caregivers who are 16 or older, who may also be living with a mental health problem or illness.

GOVERNANCE

This is a CMHA program that operates in its family support department. Programming decisions are made collaboratively with the peer facilitators as well as with input from other external advisers (local organizations, counsellors, the Health Authority, family physicians, pharmacists, etc.).

KEY INGREDIENTS FOR SUCCESS

- Co-development of the program with family caregivers.
- Peer facilitators who have experienced similar challenges create a trusting space that helps caregivers be open with each other and leads to a higher uptake of services.
- Adequate funding to provide for the basics, including refreshments at each meeting, a binder of resources for each participant, and a comfortable meeting space.

CHALLENGES

- Bridging best practice and theory with the practical goals and aspirations of peer facilitators; co-design takes time and effort to align theory and user goals.
- Implementing new practices and approaches in a jurisdiction.
- Finding volunteers as peer facilitators due to the time commitment for training and facilitating.
- Implementing a program in rural regions:
  - smaller size of population to draw from
  - stigma can be more prevalent, making it harder to find peer facilitators willing to lead the program and share that they have lived experience of caring for someone living with a mental health and/or addiction problem or illness.

EVALUATION

In addition to the evaluation of the first pilot to assess actual versus intended impact, an evaluation is conducted after every eight-week program that includes a meeting with the peer facilitators. Program participants complete a pre- and post-evaluation survey, which is both qualitative and quantitative. Content is expected to be reviewed every four years.

ACHIEVEMENTS

Effectively running a pilot and conducting evaluations and documenting testimonials throughout the implementation of this peer support model made it possible to advocate for adding peer support to other programs. This advocacy resulted in P.E.I.'s Mental Health and Addictions Services recently introducing peer support as a formal service. The success of this program has also strengthened a number of networks for CMHA as a whole.

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

Peer support needs to be implemented with special considerations in rural areas:

- The population base can be small, making it harder to find peer facilitators and participants.
- People are still more reluctant to reveal that they have a loved one living with a mental health or addiction problem or illness.

Case Study

2.

Cornwall Hospital Embrace Project

OVERVIEW

The Embrace Project is a partnership that began in 2016 among the Change Foundation's Changing CARE initiative, the Cornwall and District Family Support Group, and the Cornwall Hospital Community Addiction and Mental Health Centre. Following consultations with more than 500 caregivers and providers in the region, six project streams were created: (1) Family Inclusion, (2) Caregiver Support, (3) Provider Education, (4) Sharing Our Story, (5) Young Carers, and (6) Resource Hub. The project targets caregivers age 12 and older in the Cornwall, Stormont, Dundas, Glengarry, and Akwesasne areas of eastern Ontario.

For the first two years, the focus was on improving the caregiver experience within the inpatient mental health unit by

- supporting a culture shift toward patient- and caregiver-centred care
- creating caregiver rights
- providing caregivers with an identification badge and a welcome package
- including caregivers in discharge planning.

An Embrace Caregivers website was developed through the contribution of 52 local caregivers and providers. Work is continuing on spreading elements of the project across the hospital and into the community, as well as paying more attention to the needs of young carers and caregivers of people living with addiction.

A key aspect of the project is its collaborative approach. Teams of family caregivers, who are identified as equal partners, and health-care professionals work together in small groups on specific program goals. A co-design process is central to the work. The name "Embrace" reflects the degree of caregiver inclusion in this project.

GOVERNANCE

A small executive steering committee governs the project. Two of its five voting members are caregivers. The Change Foundation provides guidance and links the project to the provincewide Changing CARE initiative. Project planning and management are the responsibility of the project co-leads and project executive sponsor. The committee provides overall project direction on meeting its goals and oversees the budget. It meets quarterly and is directly accountable to the hospital's senior leadership team and to the Change Foundation.

As a project partner, the Cornwall and District Family Support Group serves in an advisory capacity to the project through its co-chairs, one of whom sits on the executive steering committee, while the other serves as the project's caregiver co-lead. Each year, the Embrace Project team presents a progress report and future plans to the support group. The project is guided by a formal advisory council made up of local and provincial caregiver and organizational leaders who are strategic and visionary thinkers. They provide expertise, practical knowledge, and advice at strategic points.

KEY INGREDIENTS FOR SUCCESS

- Full support for a meaningful co-design process by senior leadership and the project team.
- A governance structure that reflected caregivers as equal partners, along with adequate resources.
- A structured approach to co-design based on four pillars:
  - **Embedding caregivers in the project structure**. A caregiver is the project co-lead and works full time on the project. In addition, an 11-member caregiver working group meets monthly and is involved on many of the smaller project teams, as is the Young Carers group made up of five youths.
  - **Financial support of caregivers based on guidelines.** Guidelines were developed to financially recognize each caregiver involved in the project.
  - **Training**. Thirteen caregivers, seven providers, and six project team members received two-day training on experience-based co-design, hosted by the Change Foundation and presented by the Point of Care Foundation (U.K.). Later in the project, caregivers and providers trained together for two days on the VitalSmarts influencer model. A group of 20 (caregivers, providers, health-care leaders) travelled to Toronto for a knowledge exchange event on sustainability and spread.
  - **Communications Technology.** Time was invested to ensure caregivers were comfortable with the communication technology (Zoom) used by the project team so that caregivers were comfortable with the technology used by hospital.
- Flexible options for participating in meetings, such as teleconference and video.
- Assigning someone to make sure caregivers know about meetings, receive meeting materials, manage the financial recognition of caregivers, and answer questions in a timely manner.
- While a cultural shift to including caregivers as equal partners requires few resources, clear messaging from leadership, peers, and caregivers, and dedicating time are key to facilitating it.

CHALLENGES

- It is more difficult to get caregiver participation in rural areas, partly due to stigma around identifying oneself as a caregiver to someone with mental health or addiction concerns.
- The complexity and pace of the project often requires changes of direction or decisions by the project team and/or change initiative teams, making tracking and reporting these changes a challenge.

EVALUATION

Halfway through the project, a caregiver experience survey was conducted.

ACHIEVEMENTS

- Helped put Cornwall Community Hospital's goal, to "engage patients and families in a meaningful way in service design and delivery," into action and demonstrate the benefits and methods of co-designing with caregivers.
- Developed a range of resources:
  - The document Questions and Answers on Patient Privacy and Consent in the Addiction and Mental Health System in Ontario
  - A reference for health-care providers about obtaining patient consent
  - A process to identify and engage family caregivers with health-care providers on the inpatient mental health unit
  - A comprehensive website to help caregivers navigate the local mental health and addiction system that includes over 300 caregiver resources and a monthly calendar of local support activities
  - A 12-week course for family caregivers of loved ones with borderline personality disorder

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

The Change Foundation's *Lessons from Changing CARE* report series is a great place to find lessons learned through this and the other Changing CARE projects.

Case Study

3.

Centre for Addiction and Mental Health, Office of Family Engagement

OVERVIEW

The Office of Family Engagement (OFE) was established in September 2016 following a formal review of family engagement at CAMH. The review identified an opportunity to re-envision family engagement at CAMH. It revealed a need to align and integrate existing activities to prioritize and bring a strategic focus to family engagement across the organization (including at points of care, policy, program planning). The review found that families need a place to get information and support, that they want to have a voice as partners, and that staff need support to work with family caregivers. Based on the recommendations, the OFE leadership team used a co-design model to work with families and stakeholders to develop the family engagement strategy. This resulted in defining three key functions for the new OFE:

- Operating a Family Resource Centre (FRC). Opening in 2017, it is supported by three dedicated staff members and family volunteers. In 2018, it had more than 1,200 contacts with family members via walk-in, dedicated email, or direct phone line.
- Working with a family advisory committee (FAC), made up of family members who are part of a co-chaired committee with CAMH, whose goal is to include the family voice and perspective in all levels of work and decision making at the hospital.
- Implementing a CAMH-wide capacity building strategy for staff and leaders working with families.

GOVERNANCE

The OFE resides in the quality, patient safety, and patient and family experience portfolio of CAMH. The office reports on an annual basis to the executive leadership team, the medical advisory committee, and the clinical quality committee of the board.

Partners and stakeholders are an important part of advising the development and continued operations of the OFE. These stakeholders include families, patient partners (including the empowerment council), leadership and direct care staff of clinical programs, professional practice staff, the patient relations office, and other departments within CAMH.

KEY INGREDIENTS FOR SUCCESS

- A corporate-wide family engagement office with dedicated staff who work with families and employees to move the engagement strategy forward.
- Co-design with families: family members have been engaged from the start and at every step along the way; the office is committed to a co-design process in all aspects of development.
- Making health equity and diversity a priority: ensuring that the voice of the family reflects the community, city, and provincial population CAMH serves.
- Tying patient and family experience to quality and accountability standards, such as those from Accreditation Canada, Health Quality Ontario, and the Ontario Health Association, to prioritize the family experience and quality improvement at all levels of hospital-based care.
- Adopting the patient and family-centered care model* as a standard of practice across all clinical areas, embracing the key principles of dignity and respect, sharing timely and useful information, partnering with patients and their families in their care, and collaborating with patients and families in corporate-wide design and decision making.
- Implementing a Family Presence policy, which replaced visiting hours and recognizes that families are partners in care, and identifying what works for families' schedules and patients' clinical needs.
- Delivering training for staff in capacity building, in partnership with the professional practice office and the legal department, on respecting the legalities of privacy and consent while always treating families with respect and dignity.
- Ensuring adequate human resources for the program, which includes a manager, social worker, coordinator, an FRC facilitator, plus 10 volunteers, 10 FAC members, and a family engagement facilitator who is a family member.

CHALLENGES

Implementing culture change within the hospital is difficult. However, program leaders have found that linking the emphasis on quality improvement and client and family outcomes with their values regarding supporting client wellness and recovery journeys has helped facilitate change through a reconnection with why leaders and providers entered the mental health profession.

* As developed by the Institute for Patient and Family-Centered Care in the U.S.

EVALUATION

The program captures data on visits and calls to the FRC, including topics or themes related to what brought them in, the resources provided, referrals within CAMH and to community agencies, and if clients got what they were looking for. In addition, the locations of telephone inquiries are captured (when possible) to assess what areas of the province the program is serving.

The results of the Ontario Perceptions of Care for Mental Health and Addictions (OPOC-MHA) Survey are reviewed annually. Using its family/caregiver version, the results serve to inform the quality improvement plan, the quality councils, and the FAC.

ACHIEVEMENTS

The program's endorsement and the dedicated resources provided to it has reaffirmed CAMH's commitment to families. The Family Presence policy has helped ground the work of family engagement and experience across the hospital. Having the family/caregiver voice and perspective at the board's clinical quality committee and on the program quality councils, where most of the quality improvement and safety work is tackled, has proven invaluable for ensuring we are providing adequate support and resources to families.

LESSONS LEARNED IN ADAPTING THE PROGRAM FOR OTHER AREAS

- Looking at unique needs and mandate and adapting approaches to the context are important.
- Having corporate/leadership buy-in and resources to support the work are crucial.
- Using a co-design approach and partnering with families from the beginning lays the foundation for moving forward together. Developing a family presence policy at an organizational level also shows an institutional commitment to families.
- Building capacity and supporting expectations among organizational staff members helps foster consistency of engagement and improves the experience of care.
- Try not to re-invent the wheel: ask for help and resources – there are so many examples of great, creative engagement work that hospitals and others are doing.

Case Study

4.

Families Supporting Adults with Mental Illness in Alberta

OVERVIEW

Families Supporting Adults with Mental Illness in Alberta (FAMI-Alberta) is a grassroots movement that aims to fill gaps in service and advocate for improved treatment for family members who live with serious mental illness. FAMI-Alberta started with two angry and frustrated parents of adult children living with serious mental illness after a long journey of advocating for their children. They started making cold calls, asking tough questions, and seeking support to start the group.

Around the same time, the Alberta government, Alberta Health Services (AHS), the Canadian Mental Health Association (CMHA), and others were reaching out to better understand what caregivers needed. In 2016, the first Love You Forever boot camp, an education day with staff and caregivers, was held, and that led to the creation of the organization. FAMI-Alberta has continued ever since, in partnership with the Alberta government and AHS (Edmonton zone).

FAMI-Alberta engages caregivers in four different ways:

- one-day education workshops
- outreach and support through a website that includes a blog, Twitter, and a private Facebook group (all members are caregivers of a family member with a serious mental illness), monitored by a caregiver so members can ask questions, share stories, and learn and support each other
- monthly talks or workshops that include information, education, peer support, and advocacy
- informal one-on-one groups which, while not intentional, have been an important part of the organization for some members

GOVERNANCE

FAMI-Alberta is not incorporated, nor does it have a formal governance model. There are six individuals who form the core team, and they operate with about 12 regular members. Its operations are supported through a memorandum of agreement with CMHA Edmonton.

KEY INGREDIENTS FOR SUCCESS

- Having spokespeople who can articulate the needs of families to people in the health-care system. FAMI-Alberta has people able to communicate the pain and needs of caregivers and families navigating the system for their benefit.
- Offering cross-training at workshops (boot camp sessions), which allow staff and caregivers to learn from one another.
- The right timing. People in decision-making agencies and organizations were ready to listen and we had people who could talk and were ready to speak.
- Volunteer time.
- Funding to host the program and training events.
- In-kind support. CMHA Edmonton provides FAMI-Alberta with expert consultation from the Alberta government, AHS, and other community organizations, like private law firms, credit counselling groups, the Schizophrenia Society of Alberta, and the Eating Disorder Support Network of Alberta, who provide speakers for its boot camp and education sessions.

CHALLENGES

- There are too many issues and not enough people or energy. Those running the organization are active caregivers who also serve as committee members. Working with people who only work 8 a.m. to 4 p.m. doesn't allow for caregiving or the flexibility and empathy caregivers need.
- Being entirely volunteer run is both a challenge and a blessing. Paid staff are more constrained than volunteers in what they can do and say. It would make a world of difference if we could just get funding and be allowed to run with it. Family caregivers know what is needed, they just don't have access to it.

EVALUATION

Satisfaction evaluations are ongoing with families and staff.

ACHIEVEMENTS

FAMI-Alberta has helped to change how mental health and caregiving is understood in the community. We have gotten positive feedback from municipal councillors as well as from senior directors at AHS. We have also received referrals to our programs from AHS. When members of FAMI-Alberta ask for help within government, people respond positively. CMHA Edmonton has offered tremendous administrative support for two years, and this also shows trust in FAMI-Alberta's work.

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

- Look to see what is already in the community before you begin. Someone has likely already tried this, so connect with them and don't reinvent the wheel. Look to build and expand on what exists. All conversations should be about possibilities, not competition.
- FAMI-Alberta did considerable research before creating their own program. We found that family support agencies are mostly grassroots agencies, which grow organically and reflect the needs of the communities and the families that found and use them.
- There is always tension between those who are setting standards and local needs, which include the ability to harness the grassroots group. You need to work together to be able to be effective in what you do.

Case Study

5.

B.C. Schizophrenia Society (BCSS) and BCSS Prince George Branch's F.A.M.I.L.I.E.S.* Peer Specialists and F.A.M.I.L.I.E.S. in Residence

OVERVIEW

In 2010, the Mental Health Commission of Canada (MHCC) and its workforce advisory committee identified the opportunity to transform the mental health system in Canada through the integration and promotion of peer support. Peer Support Accreditation and Certification (Canada) (PSACC) was created to carry on the work started by the MHCC on promoting the growth, recognition, and accessibility of peer support. PSACC developed a robust certification process for Family Peer Supporters that is grounded in national standards of practice.

The British Columbia Schizophrenia Society Prince George branch (BCSSPG) and F.A.M.I.L.I.E.S. saw an opportunity to further engage family caregivers with the PSACC certification process. This included measurement and evaluation of family peer supporters' experience, knowledge, and competencies, including interpersonal relations, demeanour, communication, critical thinking, hope, self-management and resiliency, flexibility and adaptability, self-awareness and confidence, initiative and commitment, teamwork, plus continuous learning and development. BCSSPG and F.A.M.I.L.I.E.S. peer specialists completed a four-year PSACC certification process in 2018, and it is believed to be the first and possibly only PSACC-certified team in Canada. Here, two family peer supporters and a family peer support mentor, having successfully demonstrated national standards of practice, committed to strengthening family caregiver engagement in B.C.'s mental health and addiction system.

* Family Alliance on Mental Illness – Leaders in Involvement, Empowerment, and Support (F.A.M.I.L.I.E.S.)

GOVERNANCE

The BCSSPG has provided support and funding for the four-year PSACC certification process and the development of the *Family Peer Support Mentor Resource Guide*. Northern Health has identified PSACC-certified family peer support mentors as key personnel in providing program management for the future development of the Family Peer Support Mentor Leader Guide (train the trainer) to build capacity and sustain the program.

The BCSS, with the support of the B.C. Ministry of Health, provides funding for F.A.M.I.L.I.E.S. in Residence and the development of the *Family Peer Supporter Training Guide*. The F.A.M.I.L.I.E.S. in Residence quality improvement project, which is supported by the University Hospital of Northern B.C. and the adult psychiatry unit, includes patients, family caregivers, and provider partners in the planning, implementation, and evaluation of the program.

KEY INGREDIENTS FOR SUCCESS

- Accessibility to all family members (parents, partners, siblings, adult children) affected by any mental illness (psychosis, schizophrenia, depression, bipolar disorder, anxiety, trauma-related disorders, plus behaviour- and substance-related addictions) when providing family peer support in all settings (acute, community, tertiary).
- Family peer supporters recruited from families who have participated in their own journey of recovery and successfully completed the training program.
- The *Family Peer Supporter Training Guide* upholds national standards of experience, knowledge, and competencies, which trainers demonstrate in their practice, and are also included in the *Family Peer Support Mentor Resource Guide*.
- Training for new families.
- Ongoing supervision for new family peer supporters from a family peer support mentor using reflective practice.
- The development of a provincial (B.C.) family peer supporters community of practice (in progress).

CHALLENGES

Competing priorities and resistance to change among those already providing family support.

EVALUATION

Satisfaction evaluation is ongoing. In one of the hospitals a research project is underway to determine the program's progress, integration, and satisfaction levels for both families and staff.

ACHIEVEMENTS

This initiative has helped support greater accountability among family peer supporters and greater stakeholder confidence in family peer supporters, along with an increase in referrals and knowledge that peer support is safe and effective. There has been a broader recognition of organizational achievements. The PSACC-certified family peer supporters program was recognized as a quality improvement project at the 2018 Northern BC Research and Quality Conference in November. In addition, a PSACC-certified family peer support mentor was nominated for a Leadership in Quality Award from the BC Patient Safety and Quality Council, which will be presented in February 2020.

There has been an increase in the number of family caregivers being trained as family peer supporters and a greater retention of family peer supporters – some of whom have been with the organization for more than 15 years.

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

- Adopt a trauma-informed approach in supporting families.
- Recruit family members from those you have served well to gain experience as family peer supporters and provide training based on national standards of practice to increase knowledge among family peer supporters.
- Encourage and support family peer supporters to seek PSACC certification to measure and evaluate competencies.
- Participate in a family peer supporter community of practice to increase accountability and improve professional practices.

Case Study

6.

AMI-Quebec – Family Peer Support in Emergency Rooms

OVERVIEW

AMI-Quebec initiated the Family Peer Support in Emergency Rooms program to reach out to families earlier on in their caregiving journey. The program places family peer support workers (FPSW) in hospital emergency rooms (ERs) to serve as a first line of support for family caregivers. FPSWs provide information and support and encourage families to make use of available resources, either at AMI Quebec or elsewhere. FPSWs are, or have been, caregivers of someone living with a mental illness. This gives them the sensitivity and lived experience necessary to offer meaningful support.

AMI-Quebec has had a full-time FPSW at one Montreal hospital for the past six years, a part-time FPSW in another local hospital, and discussions are underway with a third hospital. FPSWs are ready to support any caregiver arriving at the hospital, whether their visit is related to mental illness, addiction, or both.

GOVERNANCE

In one hospital, the FPSW works four days per week at the hospital and one day at AMI-Quebec, where, as a team member, she attends clinical supervision and staff meetings. In the second hospital, the FPSW works two half days. Supervision of FPSWs is the responsibility of AMI-Quebec, but FPSWs are in regular contact with the ER managers. AMI-Quebec also has periodical joint meetings with the hospitals' ER departments to review progress and address arising issues.

KEY INGREDIENTS FOR SUCCESS

- Perseverance and determination are critical, as not everyone in the hospital ER will understand the value of (and therefore the need for) engaging families. Often, a culture shift needs to take place before hospital staff are fully able to value and incorporate the program into their daily practice.
- Funds to support the salaries of FPSWs are important, as well as having trained volunteers who can supplement or fill the role when funding is not adequate or available.

CHALLENGES

- Hospitals aim to stabilize crises, and the goal of the ER is to get people in and out as quickly as possible. Often, families are not considered in their own right, other than to provide immediate information about the patient.
- Changing the triage team's process to integrate a referral of families to the FPSW can be a major challenge. When referrals are not clearly and organically integrated into their work, ER staff sometimes do not encourage families to use an FPSW.

EVALUATION

Satisfaction evaluation for families and ER staff is ongoing. In one hospital, a research project is underway to study the program's progression, integration into ER processes, and family and ER staff satisfaction levels.

ACHIEVEMENTS

The FPSW program allowed AMI-Quebec to reach more people and do so earlier in their journey. The program allows FPSWs to meet families where they are rather than wait for them to find us. This has the potential to alleviate some of the burden earlier on and in a significant way.

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

- Family organizations need to drive this type of program in hospital ERs. It is unlikely that a hospital would initiate the program on its own. AMI-Quebec leadership believes strongly that wherever there is a strong family-based movement or community organization who can lobby and work within the hospital and its establishment, it can be achieved.
- Motivation, patience, and perseverance on the part of family advocates and leaders are the necessary ingredients for overcoming challenges that arise in implementing an approach like this to a clinical setting.
- Begin by reaching out to ensure the hospital institution work with the family organization as a partner throughout the process so that it becomes an integral part of the ER process, not just an add-on service. Insist on being treated as a full partner and have the hospital demonstrate a commitment to work with their teams to co-design and implement the program.

Case Study

7.

ACCESS Open Minds – Family and Carers Council

OVERVIEW

The ACCESS Open Minds (AOM) Family and Carers Council (AFC) represents families and carers and is one of six AOM stakeholder groups. AOM is a Canadian Institutes of Health Research – Strategy for Patient-Oriented Research (CIHR-SPOR) network research project led by Dr. Ashok Malla. AOM participants collaborate with youth, families, and communities across 14 sites in Canada to transform the way youth and emerging adults gain access to and receive mental health services.

AFC works to ensure that families and carers at all 14 AOM sites can participate more fully in the transformation of youth and emerging adult mental health services, as proposed by AOM. AFC also works to provide support, education, and resources to family and carers to foster the engagement, participation, and collaboration of family and carers in service transformation planning, research, evaluation, and service delivery at AOM sites.

GOVERNANCE

Currently, the AFC council is governed by the principles and guidelines of the AOM SPOR network and is self-governed through its Governance and Terms of Reference document. The AFC council has built their own governance structure with separate terms of reference while reflecting AOM's overarching principles and values. Its organizational structure includes an executive committee, constituted by the coordinator, deputy coordinator, finance officer, and secretary, who provide management and administration for the council. Subcommittees include family engagement and family peer support, communications, innovation and research, membership recruitment, communities, and culture.

KEY INGREDIENTS FOR SUCCESS

- Family and carer representation across demographics, including rural, remote, and urban centres, as well as culturally diverse populations, including Indigenous peoples, refugees, immigrants, and racialized groups
- Working together in the context of AOM objectives to promote and support family engagement with a loved one and access to family peer support
- Holding monthly meetings aimed at sharing information from the various sites and exchanging ideas about family and carer concerns, barriers, and enablers
- Holding annual in-person workshops to develop yearly action plans on family engagement and family peer support, which are shared across the AOM network and beyond
- Ongoing community mapping to identify family support resources currently available in the community, as well as those that are not aligned with the challenges and needs of the families and carers the program is in contact with
- Leadership in family engagement and family peer support in mental health care: seeking and bringing in leaders who can bring both lived experience and specific skill sets to programs (e.g., project management, education, working with groups)
- Identifying other groups and organizations in the community who have a similar mission and vision and looking for ways and opportunities to work collaboratively with them
- Developing a sustainability plan that is reasonable and doable for members
- Funding

CHALLENGES

- Developing leadership and attracting new members. People are busy, and it is sometimes difficult for them to commit a lot of time to building project capacity.
- Creating a culture change inside mental health care. Over the last few decades, service providers have been used to working on an individual basis with patients, often leaving families and carers to figure things out on their own or not including them in service and treatment planning and care outside the institution. Instituting peer support and family peer support inside an institution in an organized and valued way helps service providers integrate these services in their own patient care in a collaborative manner.

EVALUATION

Evaluation is ongoing and occurs through family and carer satisfaction surveys, annual in-person workshops for members to review activities conducted the previous year, and (recently) a qualitative survey on peer support. To date, outcomes related to AFC council participation are positive.

ACHIEVEMENTS

Since CIHR instituted the SPOR program, researchers are motivated and more interested in involving patients (and now family caregivers) in research studies in mental health. In turn, this has allowed groups like the AFC council to achieve organizational status and visibility inside health-care institutions. Within the next decade, operational family and carer councils like this one are expected to become the norm. On an individual level, families and carers created their own platform, giving families and carers an important voice and agency. The CIHR-SPOR program also raises awareness within the health-care community about the challenges that families and carers face in caring for a young person, and that their information, training, and support needs are separate from those they care for.

On a systems level, fully engaged families and carers who actively participate with the health-care team in the care and support of a loved one reduce dependence on overburdened services while contributing to significant economies in the health-care system.

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

- Find out what is already in place in your local community for family caregivers and build relationships with community members, including policy makers and decision makers, community organizations, and local businesses.
- Define the mission, vision, and objectives of the group and identify leaders and influencers to begin a group with while placing value on families and carers working within a multi-stakeholder model.
- Secure funding. An important factor contributing to the success of the AFC council is that, as part of the AOM project, it benefits from an annual budget allocation (reviewed annually by AOM and the AFC), which is meant to help support the deployment of AFC activities carrying out its mission and objectives. AFC also seeks out alternative funding opportunities to supplement and sustain its evolving and active participation in youth mental health service transformation. This budget allocation has helped remove barriers to implementing AFC initiatives and activities.

Case Study

8.

Making Family Engagement and Family Peer Support a Reality in Early Intervention Programs for Psychosis in Quebec: A CIHR-SPOR Collaboration Grant Project

OVERVIEW

This project/strategy emerged from a collaboration initiated in 2012 at the Prevention and Early Intervention Program for Psychosis (PEPP) in Montreal, led by its then-program coordinator, Dr. Srividya Iyer, members of her staff, and Ms. Mary Anne Levasseur who, as a family member with lived experience, facilitated bi-weekly family peer support groups in English and French.

With the collaboration and guidance of Dr. Srividya Iyer and Dr. Manuela Ferrari, Ms. Mary Anne Levasseur, and other family caregivers, the impact of PEPP-Montreal family peer support was assessed using an online survey. Based on the results of the survey, which were recently published in the journal, *Early Intervention in Psychiatry*,* the group applied for and was awarded a collaboration grant, jointly sponsored by CIHR-SPOR and the regional health authority, Montreal West Island Integrated University Health and Social Services Centre (CIUSSS Ouest de l' Île de Montréal). Grant project activities included creating webinars and testimonial videos and hosting a two-day consensus development conference. This conference brought together service users, families, clinicians, researchers, decision makers, and policy makers on family engagement and improving family-focused services and family peer support in early intervention programs for psychosis in Quebec.

* Levasseur, M. A., Ferrari, M., McIlwaine, S., & Iyer, S. N. (2018). Supporting family member caregivers of youth experiencing the journey into and out of first episode psychosis. *Early Intervention in Psychiatry*. Advance online publication.

GOVERNANCE

The project was governed by the terms of the CIHR-SPOR-CIUSSS grant proposal award. However, steps are being taken to transition this initiative into a strategic program on family caregiver engagement in early intervention programs for psychosis (EIPs).

The CIUSSS partnered on this project by providing funding and other resources. The project also received support from the Quebec Association for First Episode Psychosis Programs, the Quebec National Centre of Excellence in Mental Health, and the Early Psychosis Intervention Ontario Network. These organizations worked together with researchers, family members, and service users to put in place the structures necessary to ensure success.

KEY INGREDIENTS FOR SUCCESS

- Initiating collaborative partnerships with like-minded groups and key community champions
- Securing sustainable funding
- Actively including all stakeholders including family caregivers in the project from the start
- Developing a feasible work plan, co-creating webinars and mini-videos with family members, service users, and clinicians and inviting all stakeholders to participate in building consensus on avenues for action on family caregiver engagement and family peer support
- Involving policy makers and decision makers throughout the project to support the implementation and sustainability of the project and beyond
- Developing a community of practice for all stakeholders to share information and improve services
- Follow up with participants of the conference to build recommendations on how to collaborate with family caregivers and inform decision makers and policy makers
- Creating a safe space and positive environment that allows people to share experiences, brainstorm solutions to challenges, and work together to make a difference

CHALLENGES

- Garnering interest among the various stakeholders to contribute to and/or participate in the project. Once stakeholders are invested, the project will take off.
- Finding the time to plan, organize, and implement the conference. Commitment and leadership were required to drive this initiative, from pre-conference capacity building to post-conference data collection and community-building activities.

EVALUATION

A total of 87 people attended the conference. Pre-and post-conference surveys asked participants about their knowledge, attitude, and ability to promote changes in EIP programs. At this time, information is still being synthesized; however, preliminary conference results showed the conference improved people's knowledge of and attitude toward family caregiver engagement in EIPs. Emerging themes included using plain language to explain treatment and recovery plans, the necessity of involving family caregivers in programs and acknowledging their expertise, and continuing training of health-care professionals. Initial results affirm that service providers and family caregivers need to collaborate and build relationships and that creating opportunities as well as a safe space for information exchange can support the quality of care provided in EIPs.

ACHIEVEMENTS

All EIPs and EIP provincial initiatives across Canada would benefit from the success of this project model in family caregiver engagement in mental health. The foundational structure of the project, including the pre-conference capacity building, consensus-building conference, and multi-stakeholder workshops would benefit many other health-care programs seeking to increase involvement and engage family caregivers in the care and support of a loved one. This initiative was successful because all stakeholders were motivated to openly collaborate and support each other, different collaborators were listened to and their needs were respected, and mutual trust was developed throughout the project. These factors allowed for a shared vision and forward movement in improving mental health outcomes.

LESSONS LEARNED FOR ADAPTING THE PROGRAM IN OTHER AREAS

- Identify leaders and influencers to collaborate with. This includes reaching out and building relationships with community members, policy makers and decision makers, community organizations, and local businesses.
- Build a multi-stakeholder model and value family caregivers working within this model.
- Define a clear mission, vision, and objectives for the project.
- Seek funding opportunities and secure funding that can support the deployment of activities that carry out the mission and its objectives.

Appendix D

Guidelines for Recovery-Oriented Practice

RECOGNIZING THE VALUE OF FAMILY, FRIENDS AND COMMUNITY

Recovery-oriented practice and service delivery recognizes the unique role of personal and family relationships in promoting well-being, providing care and fostering recovery across the lifespan; as well as recognizing the needs of families and caregivers themselves.

CORE PRINCIPLES

- Value the role of peers, family and social networks for each as potential resources to facilitate recovery.
- Mental health practitioners acknowledge families, friends and significant others as partners and are responsive to their need for inclusion, education, guidance and support.
- Fulfilling valued roles and responsibilities within significant relationships can promote and sustain recovery efforts.
- The person experiencing mental health problems has the right to define their "circle of support" and how family members, caregivers, peers and significant others should be involved, with consideration for what is age appropriate.
- Input from family members, caregivers, peers and significant others can help inform personal recovery plans and improve the planning, organization and delivery of mental health treatments, services and supports.

MENTAL HEALTH PRACTITIONERS AND PROVIDERS…

Values and Attitudes

- Recognize and affirm the importance of a person's roles and relationships for their well-being.
- Acknowledge and affirm the ability of family members, caregivers and significant others to support a person's recovery.
- Respect the choice of the person experiencing mental health problems regarding the involvement of specific family members, caregivers and significant others.
- Appreciate the journey of discovery, healing and well-being that the family and significant others may also be experiencing.

Knowledge

- Understand the impact of mental health problems and illnesses on close relationships.
- Understand the stress placed on families when negotiating hospitalization during a crisis and the potential impact on relationships and trust.
- Understand the tensions associated with family dynamics, conflicting aspirations and the need to respect privacy and personal choices.
- Be aware of the diversity of family relationships and responsibilities, including but not limited to different cultures, same-sex relationships and blended families.
- Have up-to-date knowledge of services and supports available to meet the needs of families.

Skills and Behaviours

- Invite people to identify close relationships, express their choices and identify needs for support from significant others, and engage those identified as early as possible in the recovery process.
- Assess the needs of family caregivers and support people, and help them to navigate service systems.
- Support positive family communications and foster opportunities to maintain, establish or re-establish relationships with family and support people as part of the service plan.
- Support people to continue to fulfill important roles such as being a parent, spouse, student, employee, friend etc.
- Provide education, communication and an inviting atmosphere for family members and significant others to feel respected, welcome, safe and valued.
- Seek out and incorporate views of family members and caregivers to inform recovery practice, research and delivery of services.

REFLECTIVE PRACTICE QUESTIONS

Recovery-oriented practice

- In what ways have you offered family and other people in a person's support network continuing assistance in navigating service systems and helped them to connect with family support and advocacy groups?
- How have you supported the needs of children and young people in families experiencing mental health challenges?
- What do you do to make sure that people's choices about involving significant others are respected and re-examined regularly?
- How have you helped to mediate tensions and encouraged open dialogue when views and interests are in conflict?
- What have you done to address child custody issues to support people in fulfilling their parenting roles?
- What have you done to support people sharing their recovery goals with family and support people?

Recovery-oriented leadership

- Have you critically reviewed organizational policies and procedures to make sure they embrace working collaboratively with families, caregivers and support networks?
- What resources have been made available to support involvement of families and caregivers in program and service delivery planning?
- How have you encouraged flexibility in working with families, for example by including opportunities for off-site, after-hours and in-home assessment and services?
- What have you done to ensure that staff, people with lived experience, families and support people are aware of sources of family and caregiver support, including family peer support?
- What process do you use to assess family support needs, and how is the impact of support on family functioning measured?

OPPORTUNITIES FOR LEADERS AND MANAGERS

- Establish ongoing connections with family associations, and increase opportunities for the co-design of family peer support programs.
- Identify peer support resources for families within the community, and where these are not present, establish links with peer support specialist training groups.
- Support the use of Advanced Care Directives and substitute decision-making protocols that encourage people to share their preferences and choices with providers, families and caregivers.
- Incorporate ongoing evaluation of satisfaction levels and planning processes to improve the inclusion of, and support for, families and friends.

RESOURCE MATERIALS

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Appendix E

The Family Checklist

This checklist was developed by Leanne Needham, CMHA Peel-Dufferin, and shared with permission by staff from the Regional Family Support Program at the Royal Ottawa Hospital. It was designed to help service providers organize their interactions with family caregivers and create consistency within those interactions. The Pyramid of Family Care was used to develop the checklist to help providers think about which level of care and resources might most appropriately meets the needs of family caregivers.

THE FAMILY CHECKLIST

- ☐ Welcome Package
- ☐ Explain your role of worker and/or team
- ☐ Explore expectations of family regarding service and discuss confidentiality/consent
- ☐ Explore the family's past interactions with the mental health system

HAS THE FAMILY MEMBER RECEIVED ANY OF THE FOLLOWING SUPPORTS IN THE PAST?

- ☐ Seen the GP regarding own ability to cope or to talk about loved one's illness
- ☐ Received information from professionals regarding mental illness/treatment/recovery
- ☐ Found information on own through books/internet/community
- ☐ Been to a support group
- ☐ Attended educational programs or workshops for families
- ☐ Sought counselling as an individual or with loved one involved
- ☐ Explore family's beliefs, attitudes, knowledge about loved one's illness

- [ ] Explore what family needs to help them cope
- [ ] Are there signs of caregiver burnout?
- [ ] Would the family benefit from being connected to other agencies?
- [ ] Does the family want to be contacted regarding any workshops, events, or support groups that happen for families?

INTRODUCING THE IDEA OF WORKING TOGETHER

- We want to help you understand what may be going on with your loved one and also want to hear your impressions of what is going on so that we can be better informed.
- Research has shown us that when families are well supported and educated about mental illness their loved one in turn does better, so we want to work with you and make sure you also get any support you may need.
- Because of this we would like to understand what you have been through as a family member or with the mental health system, so that we can be sure to support you to the best of our ability.
- Would you be comfortable sitting down with me and talking to me about your concerns or talking to me about the impact that your loved one's illness has had on you?

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Mental Health Commission of Canada
Commission de la santé mentale du Canada

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MENTAL HEALTH COMMISSION OF CANADA

Suite 1210, 350 Albert Street
Ottawa, ON K1R 1A4

Tel: 613.683.3755
Fax: 613.798.2989

mhccinfo@mentalhealthcommission.ca
www.mentalhealthcommission.ca

@MHCC_ /theMHCC /1MHCC @theMHCC
/Mental Health Commission of Canada