



Mental Health  
Commission  
of Canada

Commission de  
la santé mentale  
du Canada

# Moving Forward Together:

A Multi-Stakeholder Dialogue on Meeting the  
Needs of Family Caregivers of People Living with  
Mental Health and Addiction Problems or Illnesses

March 2, 2018  
Ottawa, ON

[mentalhealthcommission.ca](http://mentalhealthcommission.ca)



The views represented herein solely represent the views of the Mental Health Commission of Canada. Production of this material is made possible through a financial contribution from Health Canada.

# Table of Contents

Opening Remarks ..... 4

Introductions, Interests and Concerns ..... 5

Objective 1: Taking Stock..... 6

Objective 2: Identifying Good Practices, Core Values and Desired Outcomes for Improving Family/Caregiver Engagement. 8

Objective 3: Mobilizing Action Toward Desired Outcomes ..... 11

Moving Forward ..... 15

Closing Remarks ..... 15

Appendix A – Dialogue Participants..... 16

# Opening Remarks

**Louise Bradley**, President and CEO of the Mental Health Commission of Canada (MHCC), opened the event by making a request to those in attendance: to help the Commission identify the common threads that run through their individual stories as family caregivers. Though the exact details may differ, there are shared themes. Frustration toward a system that seems impervious to change. Humility in the face of the considerable task of caring for a loved one living with a mental illness or addiction. And tenacity in drawing attention to the issues faced by family caregivers.

Bradley invited participants to channel these commonalities and experiential knowledge to help MHCC hone in on key priorities and pressing needs. “If we want to write a new chapter in mental health, one that honours input, experience and the needs of family caregivers, we have to put our heads together,” she said. “I can’t promise we will be able to ease every challenge, knock down every hurdle and bridge every gap... but I do know that if we put our collective expertise to work, we can come up with some concrete actions.”

Progress toward better supports for family caregivers has been gradual. Family caregivers contribute millions of dollars in unpaid labour to the healthcare system — and policymakers have finally begun to take notice, as reflected in changes to federal leaves for caregiving and the evolution of workplace standards for caregivers. But the unique needs of caregivers of people with mental illnesses and addiction are far broader.

This event marks the first step in laying the foundation for addressing those needs. Bradley acknowledged there’s a lot of work ahead but also a lot of strength to build on, including a shared conviction that recovery is the best way forward.

Following Bradley’s opening remarks, event facilitator **Suzanne Taschereau** outlined the objectives for the day:

- Take stock of service system supports and engagement of family caregivers of people living with mental health and addiction problems or illnesses.
- Identify good practices and desired outcomes to improve family caregiver engagement and supports across Canada in the next three years.
- Identify key leverage points, priority actions and stakeholders to engage with to move toward the desired outcomes in the next year.
- Provide participants with renewed energy, new connections and a commitment to concerted action to increase impact.

# Introductions, Interests and Concerns

After introducing themselves to the larger group, participants shared what they were most interested in exploring during this event. Others noted concerns related to challenges family caregivers face.

## Participants were interested in exploring how to:

- Foster productive dialogue
- Establish partnerships between families, providers, organizations and other stakeholders
- Disseminate evidence-informed practices into hospitals and caregiver support groups
- Apply recovery models to caregiver-specific experiences
- Identify and scale successful programs
- Make family members part of the healthcare team
- Involve families in the design of programs and supports
- Include mental illness and addictions as part of broader national and provincial dialogue around caregiving
- Drive recognition that mental illness and addiction are a family affair, not just a service user issue
- Sustain caregiver engagement
- Ensure families, caregivers, youth and service providers see one another as assets
- Address communication gaps between clinicians and families
- Share best practices to avoid duplication of effort
- Adapt best practices to other communities
- Address stigma, including in the provider community
- Secure more funding for community programming
- Capitalize on experiential knowledge through peer support
- Improve caregiver access to evidence-based practices
- Ensure accountability of mental health services and accessibility for families and caregivers
- Make the health system a positive, supportive experience for caregivers
- Unify voices of caregivers, including those who don't recognize themselves as such
- Support caregivers throughout the care journey, not just at the first point of contact

## Others expressed concerns about:

- The many roles family caregivers have to take on (caregiver, advocate, etc.) — sometimes at the risk of their own health
- Caregiver stress management
- The aging population and how it relates to caregiving
- The lack of recognition of the importance of siblings in the lives of people who suffer from mental health or addiction
- Absence of voices of people from minority populations, the LGBTQ community and other marginalized groups
- The length of time it will take to achieve adequate support for family caregivers
- Financial security for caregivers
- Privacy policies that prevent family caregivers from being informed of a loved one's condition when they're discharged from hospital
- Lack of support for caregivers within rural settings, as well as caregivers who are supporting loved ones who don't have a diagnosis

# Objective 1: Taking Stock

In this panel discussion, four people actively engaged in moving the family caregiver agenda forward talked about current and future issues and opportunities: **Cynthia Clark** of the Ontario Family Caregivers Advisory Network (OFCAN); **Ella Amir** of AMI Québec; **Shaleen Jones** of Peer Support Canada; and **Maureen O'Connor** of the Health Standards Organization (HSO).

*Who and what informed the development of the Guidelines?*

- When MHCC first began to include people with lived experience in its discussions, family caregivers remained on the sidelines. **Ella** said that recognizing the importance of caregivers as partners has been a gradual process. The Guidelines, which were the culmination of the work done by the MHCC's Family Caregivers Advisory Committee, were developed in close consultation with caregivers, people with lived experience and system planners. While its recommendations were aimed at policymakers and service providers, it was recognized from the start that the onus would be on family associations and individual caregivers to push the agenda forward.

*What progress has been made since the release of the Guidelines?*

- For **Cynthia**, the biggest change is that “we’re on the radar.” Fifteen years ago, it would have been unusual for somebody to represent family caregivers on committees of places like the Royal Ottawa Mental Health Centre — but that has changed. While institutions are starting to look at the Guidelines, more work needs to be done to engage with service providers.
- **Ella** said that while progress has been made, change doesn’t come easy or fast, especially in hospitals. There’s still not enough family peer support in emergency departments — and while hospitals have embraced some of the Guidelines’ recommendations, actually implementing them has proven to be a challenge. In comparison, community-based organizations are much faster to buy into change.
- **Shaleen** agreed, saying the real champions have come from community-based organizations, which are launching amazing programs to work more closely with families. Considerably less enthusiasm for the Guidelines has been seen in the formal mental health care system.

*What initiatives has the Health Standards Organization been undertaking in this area?*

- **Maureen** said HSO implemented family- and client-centred care into the criteria for its standards a few years ago. One-quarter of its technical committees are now made up of patients and family members, ensuring they have a direct influence on the standards.

*Looking ahead, what are the major concerns and priority issues to be addressed?*

- **Cynthia** stressed that family caregivers of people living with mental health issues have special and specific needs that must be uniquely recognized and resourced, not just lumped into the same line item with all other caregivers.
- Sustainability and funding are the most important issues for **Ella** — but it must be recognized that different communities will have different priorities. It will be important to create collaborative partnerships and continue to promote existing ones.
- More opportunities are needed to scale up and share knowledge, said **Shaleen**. When it comes to system reform, families are a largely untapped resource who can do a lot of the heavy lifting.

*As we look to future, what are some key opportunities to accelerate the process?*

- **Cynthia** noted the Change Foundation as an organization that is doing good work in engaging families and valuing their contributions.
- Mental illness and addiction are family affairs, said **Ella** — and both families and the system must recognize that fact. The needs and challenges of young carers must also be acknowledged.

- For **Shaleen**, knowledge exchange and creating opportunities for people to come together to hear about all of the great projects being done will be essential. We also need to look for ways to connect and collaborate with other organizations who aren't currently in our "sandbox".
- **Maureen** said the HSO's mental health and addiction standard is currently being revised and, in May 2018, there will be a 60-day public consultation where people can provide input on the new standard. All comments submitted online will be reviewed by the technical committee.

*How do we get more buy-in and understanding of the importance of family members from frontline staff?*

- **Cynthia** said personal stories are the key to helping staff understand the importance of engaging with families.
- For **Ella**, buy-in is not an event but the result of a process. Perseverance is the only way to make change happen.

#### **Q&A HIGHLIGHTS**

Following the panel discussion, other meeting participants voiced the following comments:

- One way to get buy-in is to develop measures for access and quality of service, as well as a standard that sets clear expectations for involving family in initial assessments and continuing care. Maureen added that it's important to hold organizations accountable — and if they aren't quite there, to make sure they know what they need to work toward.
- In hospitals, family members are struggling to get through each day but aren't getting enough support from the system. Community organizations have the experience to train on-site service providers or even deliver in-house family peer support. Getting buy-in is hard, though, as both service providers and their managers need to be convinced of the value of this training.
- Nurses are advocating for families as best as they can and want to implement the recommendations of the Guidelines, but we need to recognize the challenges they face. Workloads are increasing but funding is not, meaning they don't get as many professional development opportunities as they used to. In addition, many hospitals are replacing registered nurse positions with less-skilled registered practical nurses.
- Some participants felt strongly about the shift in terminology from "caregiver" to "carer", saying the change was made without consulting caregivers. It's important to use language they identify with and understand. Also, the change may be confusing for employers, who have been asked to be more understanding of caregivers but to implement a standard that refers only to carers.

# Objective 2: Identifying Good Practices, Core Values and Desired Outcomes for Improving Family/Caregiver Engagement

After the panel, participants took part in an “appreciative inquiry” process, which tasked them with identifying:

- **Best practices** for supporting and meeting the needs of family caregivers
- **Core values** that drive engagement with family caregivers or people with lived experience
- **Wishes for the future** of support systems and engagement of family caregivers and people with lived experience

Participants identified items within each category individually before sharing and consolidating with others at their tables. MHCC staff then clustered all of the contributions into themes.

## ***BEST PRACTICES***

### **Culturally sensitive practices**

Caregiver supports must take into account differences in values, family structures, modes of treatment and other factors. Strategies should be co-developed with whatever groups they’re intended to treat: First Nations, LGBTQ2+, and immigrant, refugee, ethno-cultural or racialized (IRER) populations, etc.

### **Culture shift**

A culture shift is needed to fully support those caring for loved ones who have a mental illness or addiction. This shift must include transitioning to strengths-based language, incorporating caregiver stories to drive change, and adopting a proactive approach to mental health (i.e., building resiliency) rather than a reactive one.

### **Partnership**

It is important that service providers see families as partners in the treatment team. There should be mandatory education for clinicians around family-centred care and education for families regarding their rights and role in treatment, self-care and effective communication. Family caregivers should also serve as advisors on hospital committees and working groups to ensure that perspective factors into decisions.

### **Training**

Clinician training programs should be co-developed or delivered by caregivers to ensure the issues they face are adequately reflected and addressed. Actor-based training scenarios and other methods could also be used to teach clinicians ways of engaging and involving family caregivers in the treatment journey and to reinforce its importance.

### **Innovation**

Online support groups and resources, sibling programs and high-quality first-episode psychosis services were identified as existing or potential innovations in support for family caregivers.

### **Communication between families and service providers**

Family caregivers are best supported when the lines of communication with service providers are open. This may necessitate breaking down silos, improving communication skills, and devising ways to share programs and resources more effectively.

### **Peer support**

Other family caregivers can be a huge source of support. They can offer information, resources and support to families in crisis until the family is able to access professional services, or simply provide a sympathetic ear and empathize with what the family is going through. Opportunities for peer support should be created (e.g., by making peer support available through hospital services).

## Policy

Changes to organizational and federal policies that support family caregivers should be promoted. This includes federal supports such as the tax credit for family caregivers, and changes to organizational cultures and standards to hold organizations accountable for remedying the issues family caregivers face.

## Caregiver-led

Family caregivers' experiential knowledge is highly valuable and must be recognized as such. Families should be engaged as educators through peer support and as co-developers of new programs. This should include monetary compensation because filling the role of family caregiver requires time and can carry a financial burden.

## Resources

Participants identified some resources for family caregivers and examples of best practices:<sup>1</sup>

- Plain-language books about mental health and addiction problems or illnesses, such as those in the *For Dummies* series *Making Privacy and Consent Rules Work for Family Caregivers* (available at [change.foundation.ca/site/wp-content/uploads/2017/11/Privacy-and-Consent-report\\_Final.pdf](https://change.foundation.ca/site/wp-content/uploads/2017/11/Privacy-and-Consent-report_Final.pdf))
- Family Caregivers of British Columbia's provincial toll-free support line, self-care resources and online support groups (available via [familycaregiversbc.ca](http://familycaregiversbc.ca))
- A collaboration agreement to be signed between regional *Centres intégré de santé et de services sociaux (CISSS)* and community organizations to ensure the inclusion, engagement and consultation of family caregivers. This agreement was included as part of Quebec's provincial Mental Health Action Plan (2015-2020).

## CORE VALUES

Participants identified the following core values:

- **Recognizing the value of family caregivers** and their stories, experiential knowledge and expertise — and providing space for caregivers to share these things
- **Building capacity** among service providers for managing family distress quickly and effectively, as well as for self-care among caregivers (e.g., coping strategies, self-directed cognitive behavioural therapy)
- **Communicating** openly with caregivers and **listening** to what they have to say with empathy and without judgment
- **Empowering caregivers** to influence change
- **Respecting** the dignity and expertise of family caregivers and their loved ones and fostering genuine, meaningful engagement
- **Promoting equity and social justice** by supporting and protecting the vulnerable, recognizing caregiver **diversity** (e.g., culture, age, desire for involvement) and approaching mental health as a human rights issue
- **Engaging caregivers** through co-design (i.e., working with families to influence and inform change) and by establishing equal, effective **partnerships** between caregivers, service providers and government
- **Validating the experiences** of caregivers and **working against stigma** at the institutional, community and system levels to normalize the experiences of mental illness and addiction
- **Engendering hope** for recovery

---

<sup>1</sup> An appendix to this meeting report lists resources provided by participants in an advance online survey.

## ***WISHES FOR THE FUTURE***

### **Quality standards / accountability**

One way to increase accountability of family caregivers and caregiving organizations will be through regulated practice and the use of quality indicators. In general, we need to move from guidelines to standards and accountability mechanisms to work toward their universal adoption across the entire system.

### **Education and skills development**

Training on caregiver needs — and how to engage and communicate with families and caregivers — should be incorporated into post-secondary and continuing education healthcare programs. Education on this topic also needs to be offered to healthcare providers across the continuum of care, not just specialists in mental health and addictions.

### **Funding**

Sustainable funding to support family caregivers is key. This might include compensating family caregivers for their work. For caregiving organizations, funding should be linked to specific outcomes and quality indicators. To ensure funding to support family caregivers is included in the budgets of community-based organizations and healthcare institutions, we will first need to make the case to justify a shift in resources.

### **Scaling up**

We must invest in scaling up successful programs and services, sharing those that are proven to be helpful.

### **Family engagement in program and policy development**

Families must be an integral part of the care team. That means healthcare professionals need to understand and value the role family caregivers play — with family engagement and inclusion enshrined in healthcare organizations' missions, visions and value statements. Ensuring a family lens is applied to program and policy development will require a culture shift, moving from token consultation to true partnerships.

### **Integrated care**

Interprofessional, integrated and holistic services would help avoid duplications and address gaps in the system. Organizations need to break down silos and strive for greater cross-sector involvement.

### **Services and supports for caregivers and families**

Families need to be supported at every stage of the care journey through options and resources regarding levels of engagement, financial support, respite and more. Family mentors could help build the capacity to provide such support. At the same time, caregivers require an easy-to-access repository of resources. They also need more specialized resources, such as a crisis support line for when they need immediate help.

### **Advocacy**

Strong, sustainable advocacy involves community groups and family caregivers speaking with one voice and working collaboratively, sharing programs and information between groups and across provinces. Advocacy efforts can include showing how caregivers impact the bottom line or a campaign to help family caregivers self-identify as such so they are comfortable coming forward for help.

### **Recognition of distinct populations**

Specific work needs to be done in partnership with and led by populations with distinct needs, including Indigenous populations, rural communities and francophone communities.

# Objective 3: Mobilizing Action Toward Desired Outcomes

Through a “dotmocracy” exercise, participants voted on which themes under the “wishes for the future” category they think MHCC should prioritize going forward. Five top priorities emerged:

- Education and skills development
- Family engagement in program and policy development
- Services and supports for caregivers and families
- Quality standards / accountability
- Advocacy

MHCC noted that the selection of these specific priorities doesn’t mean that others won’t be considered in the future. Prioritization will simply help focus efforts on advancing key priorities within the next three years, with other recommendations picked up by MHCC and other stakeholders afterward.

---

## Taking action on the top priorities

Tables were assigned to one of the five identified priorities. Participants at each table were asked to consider the following about the priority in question:

- Who needs to take action/change to achieve desired outcomes?
- What actions need to be taken?
- How can we mobilize actors to act and align their efforts for greater impact?

Groups discussed these questions and recorded their thoughts on flipcharts. One person from each group then presented their group’s ideas to the other participants.

### ***EDUCATION AND SKILLS DEVELOPMENT***

Service providers are in a prime position to help meet the needs of family caregivers. This can be accomplished in part by fostering organizational cultures that encourage providers to recognize that caregivers and families must be part of patients’ recovery.

Curricula and training programs should reflect this value and build the capacity of service providers to deliver care this way. MHCC could develop a comprehensive plan with consistent messaging for provider groups. This would involve engaging service providers to identify knowledge and skill gaps, and engaging with caregivers and patients to understand what they see to be gaps among service providers. The new curriculum should be co-designed with patients and family, and embedded in standards and budget groups to promote adherence.

WHO	
<ul style="list-style-type: none"><li>• First priority: Professionals<ul style="list-style-type: none"><li>○ Service providers — frustrated; inclusive; peers</li></ul></li><li>• Second priority: Families<ul style="list-style-type: none"><li>○ “What do I need to know to move forward with recovery?”</li><li>○ “What are my rights?”</li></ul></li></ul>	<ul style="list-style-type: none"><li>• Others<ul style="list-style-type: none"><li>○ Colleges/universities</li><li>○ Professional associations</li><li>○ Employers</li><li>○ Insurers</li><li>○ Policymakers</li></ul></li></ul>

WHAT	
<ul style="list-style-type: none"> <li>• Culture change               <ul style="list-style-type: none"> <li>○ Include mental health caregiver perspectives in healthcare provider curriculum</li> <li>○ Training on information, support and participation co-developed with patients and families</li> </ul> </li> <li>• Education for modules in college/university, healthcare programs on caregiver needs and engagement</li> </ul>	<ul style="list-style-type: none"> <li>• Education around communication between family caregivers and service providers based on respect</li> <li>• Promote openness to using alternative treatments like hypnosis, mindfulness, meditation, yoga, etc.</li> <li>• Disseminate local/global resources (info/compile)</li> <li>• Plain-language docs for caregivers and patients (e.g., fact sheets)</li> <li>• Teach advocacy skills to caregivers</li> </ul>
HOW	
<ul style="list-style-type: none"> <li>• Comprehensive, cohesive and strategic national plan</li> <li>• Agreement across disciplines (small – incrementalism → spread)</li> <li>• Synthesis → common wisdom → current practices</li> <li>• Consulting caregivers, people with lived experience</li> </ul>	<ul style="list-style-type: none"> <li>• Providers → where are their gaps in knowledge?</li> <li>• Find champions</li> <li>• Budget/proposal</li> <li>• Embed into standards</li> <li>• Navigator; information fair</li> </ul>

#### **FAMILY ENGAGEMENT IN PROGRAM AND POLICY DEVELOPMENT**

When talking about programs and policies, how we achieve the “what” will change from system to system, with different strategies needed for the healthcare system versus the social or correctional systems. It will be important to map the experience of caregivers through these systems as we don’t yet know what that trajectory looks like. This will help us identify gaps and understand where more resources and family involvement are needed in developing and revising policies.

A repository of resources will help local and provincial family caregiver groups learn from what others are doing across the country. More work also needs to be done to educate family caregiver groups on how to recruit and train new members. Finally, caregivers are tired or telling and hearing the same story over and over again. Are there more compelling ways of turning data into creative storytelling to better influence our changemakers?

WHO	
<ul style="list-style-type: none"> <li>• Service delivery groups and professional organizations</li> <li>• Government</li> <li>• Allies in government (e.g., SPOR)</li> <li>• Government advisory groups (e.g., CADTH, Health Quality Ontario)</li> <li>• MHCC</li> <li>• Caregivers</li> <li>• Family caregiver associations</li> </ul>	<ul style="list-style-type: none"> <li>• Families</li> <li>• Youth</li> <li>• Service providers</li> <li>• Workplaces/employers</li> <li>• Community organizations (with representation on boards, hiring tables and working groups)</li> <li>• CEOs and other leaders</li> <li>• Research groups</li> <li>• Citizen engagement associations (e.g., IAP2)</li> </ul>
WHAT	
<ul style="list-style-type: none"> <li>• Purposeful engagement (e.g., what is the outcome going to be?)</li> <li>• Cross-sector collaboration</li> <li>• Mapping the family experience to show transition points and where families get lost</li> <li>• Evaluating the caregiver experience in the engagement and quality improvement process</li> </ul>	<ul style="list-style-type: none"> <li>• Educating, motivating and preparing people for engagement</li> <li>• CARMEN framework</li> <li>• Recruiting families and caregivers to the table</li> <li>• Building cohesion across the country among people who have similar goals</li> <li>• Building awareness across diverse groups</li> <li>• Empowering families to participate in change</li> </ul>

HOW	
<ul style="list-style-type: none"> <li>• Compensate families and caregivers for their engagement (using the Change Foundation as a tool to identify the best way to compensate)</li> <li>• Support caregivers throughout the engagement process beyond financial compensation</li> <li>• Leverage the Change Foundation’s report on engagement</li> <li>• Alleviate barriers for caregiver engagement and participation (e.g., respite, travel)</li> <li>• Track the process/phases of family engagement</li> <li>• Case studies that emphasize this is a family health issue, not individual</li> </ul>	<ul style="list-style-type: none"> <li>• Learn best practices from different provinces</li> <li>• Get data from discussion groups and analyze the themes</li> <li>• Share existing programs and policies</li> <li>• Connect with and leverage caregiver groups across Canada that target different systems (e.g., hospitals, community mental health, correctional)</li> <li>• Digital storytelling with family caregivers (e.g., blogs, mobile apps)</li> <li>• Document weekly hours of support</li> </ul>

**SERVICES AND SUPPORTS FOR CAREGIVERS AND FAMILIES**

Every family caregiver and family member should know what services and resources available to them and how to access them. To make that happen, we need to build a centralized knowledge exchange hub for services and resources at the national and provincial levels: something that is intuitive and user-friendly, and frequently updated to reflect the needs of family caregivers.

Because not everyone self-identifies as a family caregiver (and therefore might not seek out this type of service), a marketing and public relations campaign will be needed to make sure the public knows the hub exists. The next step would be to work with caregivers and people with living experience to look at what might be missing from the hub and then figure out how to fill that gap, possibly by taking something that’s being done locally and scaling it up to the national level.

WHO	
<ul style="list-style-type: none"> <li>• Public sector</li> <li>• Elected officials</li> <li>• Caregivers</li> <li>• Caregiver organizations</li> <li>• MHCC</li> <li>• CMHA</li> <li>• Health Canada</li> <li>• Technical support and web design experts (to build user-friendly, intuitive resources)</li> </ul>	<ul style="list-style-type: none"> <li>• HSO</li> <li>• Accreditation Canada</li> <li>• General practitioners</li> <li>• Family peer support workers</li> <li>• Walk-in clinics</li> <li>• Professional oversight bodies</li> <li>• People with living experience</li> <li>• Celebrities</li> <li>• Schools and guidance counsellors</li> </ul>
WHAT	
<ul style="list-style-type: none"> <li>• Centralized database/hub of knowledge and resources, accessible in diverse formats (e.g., phone, web)</li> <li>• Marketing and public awareness campaigns</li> </ul>	<ul style="list-style-type: none"> <li>• Navigator to help equip caregivers with the right resources and services at the right time</li> <li>• Creating new resources that caregivers identify as necessary</li> </ul>
HOW	
<ul style="list-style-type: none"> <li>• Leverage existing resource databases</li> <li>• Leverage existing navigators and peer supports (internal champions)</li> <li>• Look at existing initiatives to scale up what works</li> </ul>	<ul style="list-style-type: none"> <li>• Find opportunities for innovation</li> <li>• Videos</li> <li>• Hashtags</li> <li>• Make it simple for non-traditional referrals</li> </ul>

## QUALITY STANDARDS / ACCOUNTABILITY

This group thought back to before the *Mental Health Strategy for Canada* was developed, when there were many different strategies in place at all different levels across the country. Before doing anything, we need a map of the strategies and standards that currently exist today. We should review where each province and territory are when it comes to family engagement — and MHCC is in a good position to do that.

One of the most frustrating things about standards is that while they can be written, how do we know they are being implemented and followed through? Is there a scorecard or measurement for accountability that could be adopted? For places that are just starting out with family engagement, they will need easy-to-implement tools to determine whether they're doing it correctly.

WHO	
<ul style="list-style-type: none"> <li>• Accreditation Canada</li> <li>• Health Canada</li> <li>• Provincial health systems</li> <li>• All three levels of governments</li> <li>• Associations and agencies</li> </ul>	<ul style="list-style-type: none"> <li>• Federation of Canadian Municipalities</li> <li>• Ontario Hospital Association</li> <li>• MHCC</li> <li>• PSOC (Quebec)</li> </ul>
WHAT	
<ul style="list-style-type: none"> <li>• Review of existing family engagement practices in other medical fields</li> <li>• Review of existing mental health support ecosystems in every province</li> <li>• Environmental scan across Canada of existing quality standards and indicators</li> <li>• Reducing duplication of standards</li> </ul>	<ul style="list-style-type: none"> <li>• Quality indicators</li> <li>• Accreditation standards training, strategies and report cards for every province (for knowledge transfer but also to shame those that are not meeting the criteria)</li> <li>• Principles at the system level</li> <li>• Identifying barriers and challenges</li> </ul>
HOW	
<ul style="list-style-type: none"> <li>• Evidence-based audit of family engagement</li> <li>• Include families in co-design of performance measures</li> <li>• Adopt common standards and indicators at the national level</li> </ul>	<ul style="list-style-type: none"> <li>• Look at what other countries are doing</li> <li>• Have a template contract between government bodies and community organizations for mental health, including forms that can be signed to allow information to be shared with families</li> </ul>

## ADVOCACY

Promoting respect and dignity for caregivers, reducing stigma around mental illness and addiction, and removing barriers to services and support systems are key advocacy goals. A broad set of actors could be engaged to promote these agenda items, including families, governments, non-profits, institutions and celebrities.

Anti-stigma should be a core part of advocacy because “what is good for the patient is good for the caregiver.” Objectives include changing the idea that mental illnesses or addictions are somehow less significant than physical ailments, as well as raising awareness of how many people are affected by them. Possible actions include a national awareness campaign that includes media blitzes, publicity for Canada’s National Caregivers Day on April 4, and other ways of engaging the public.

WHO	
<ul style="list-style-type: none"> <li>• Government</li> <li>• Families</li> <li>• Individuals</li> <li>• Institutions</li> <li>• Non-profits</li> </ul>	<ul style="list-style-type: none"> <li>• Individual hospitals</li> <li>• Universities and schools</li> <li>• General population (industry, workplaces/employers)</li> <li>• Celebrities (people of influence)</li> </ul>

WHAT	
<ul style="list-style-type: none"> <li>• Normalization (human rights issue) <ul style="list-style-type: none"> <li>○ Mental health on par with physical health</li> <li>○ Respect and dignity (empathy)</li> <li>○ Removing stigma</li> <li>○ Take away depersonalization</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Removing barriers</li> <li>• Changing the language</li> <li>• Re-examining societal values (top-bottom, bottom-top)</li> <li>• Validating that mental illness is an illness</li> </ul>
HOW	
<ul style="list-style-type: none"> <li>• Lobbying (government)</li> <li>• Counter uninformed posts on social media</li> <li>• Promote National Caregivers Day, with a focus on mental health</li> <li>• Flyers to educate</li> <li>• Finding allies to connect families</li> <li>• Personalize it</li> </ul>	<ul style="list-style-type: none"> <li>• National awareness campaign/local/provincial <ul style="list-style-type: none"> <li>○ Media blitz (print, television)</li> <li>○ Government recognition of National Caregivers Day</li> <li>○ Workplace sensitivity to caregivers</li> <li>○ Seminars for employers to break down barriers</li> </ul> </li> </ul>

## Moving Forward

A large group discussion followed the group presentations. One participant raised a concern that the fracturing of family caregivers into groups based on illnesses weakens the group overall and will hinder progress going forward. Individual caregivers and caregiver organizations must break down these silos, band together and refrain from competing over whose story is worse. Doing so will facilitate many of the ideas brought up at this event and will put caregivers in a better position to advocate for things like government funding.

After that discussion, MHCC staff thanked participants for all of the passion and thought they put into the event and for providing the Commission with direction for future action. The next step will be to develop a knowledge translation plan to promote uptake. The Commission will also continue working with the family caregivers advisory group and is committed to putting together an awareness-raising social media campaign to mark National Caregivers Day. This will include developing core messages participants can share through their own social media channels and networks.

## Closing Remarks

Suzanne reminded the group that they started the day with four main objectives: take stock of the priorities and issues at hand, look at existing best practices, identify initial opportunities for actions, and leave with new connections and ideas so we can move the agenda forward with determination.

Echoing back to the opening exercise, Suzanne concluded the day by asking each person for a single word to describe how they're feeling going forward. Some of the responses included:

- |              |                |              |
|--------------|----------------|--------------|
| • Inspired   | • Reconnected  | • Privileged |
| • Optimistic | • Rejuvenated  | • Affirmed   |
| • Focused    | • Enriched     | • Aware      |
| • Passionate | • Encouraged   | • Empowered  |
| • Hopeful    | • Determined   | • Impressed  |
| • Curious    | • Appreciative | • Thankful   |

# Appendix A – Dialogue Participants

Ella Amir	AMI Quebec\AMI Québec
Ajay Pandhi	Canadian Association of Social Work\Association canadienne des travailleurs sociaux
Katie Fleming	Canadian Centre on Substance Use and Addiction/Le Centre canadien sur les dépendances et l'usage de substances
Tayte Willows	Canadian Mental Health Association, PEI/L'Association canadienne pour la santé mentale, IPE
Roger Stoddard	Canadian Mental Health Association/L'Association canadienne pour la santé mentale, NB & Family Advisory Council, Horizon Regional Health Authority
Greg Kyllo	Canadian Mental Health Association/L'Association canadienne pour la santé mentale -National
Laureen MacNeil	Canadian Mental Health Association/National/L'Association canadienne pour la santé mentale- Calgary
Ashley Chisholm	Canadian Nurses Association\Association des infirmières et infirmiers du Canada
Debbie Cameron-Laniga	Caregivers Association of Alberta
Angus Campbell	Caregivers Nova Scotia
Miriam McCann	Centre for Addiction and Mental Health (CAMH), Office of Family Engagement
Lori Hale	Change Foundation
Nicole Comin	Early Psychosis Program, Yukon Health and Social Services
Stephanie Lee	Eating Disorders Foundation of Newfoundland
Michelle Hebert Boyd	Eating Disorders Nova Scotia
Sydney Graham	Families for Addiction Recovery
Janet McLean	Family Caregivers Association of BC
Robin Brown	Family Smart
Violaine Lacroix	Fédération des familles et amis de la personne atteinte de maladie mentale (FFAPAMM)
Claudia Houle	Health Standards Organization\L'Organisation de normes en santé
Maureen O'Conner	Health Standards Organization\L'Organisation de normes en santé
Nicholas Watters	Mental Health Commission of Canada\Commission de la santé mentale du Canada
Liz Wigfull	Mental Health Commission of Canada\Commission de la santé mentale du Canada
Bonita Varga	Mental Health Commission of Canada\Commission de la santé mentale du Canada
Francine Knoops	Mental Health Commission of Canada\Commission de la santé mentale du Canada
Dave Gallson	Mood Disorders Society of Canada\La Société pour les Troubles de L'Humeur du Canada
Lisa Young	Nursing, Royal Ottawa Hospital, Ottawa\Soins infirmiers, Le Royal, Ottawa
Christine Holland	Ontario Family Advisory Councils Network
Cynthia Clark	Ontario Family Advisory Councils Network
Vanessa Pok Shin	Operational Stress Injuries Services and Supports, Defence Canada\Programme de Soutien social aux blessés de stress opérationnel, Defense Nationale
Shaleen Jones	Peer Support Canada - Canadian Mental Health Association/L'Association canadienne pour la santé mentale -National
Mary Anne Levasseur	Programme d'évaluation, d'intervention et de prévention des psychoses (PEPP-Montréal) , L'Institut Douglas/Douglas Institute
Hazel Meredith	Schizophrenia Society of BC, Victoria
Chris Summerville	Schizophrenia Society of Canada & Manitoba\ Société Canadienne de la Schizophrénie
Dave Banko	Schizophrenia Society of NFLD
Antonella Scali	Schizophrenia Society of Ontario
Simon Columbe	Sir Wilfrid Laurier University, Psychology
Lori Wozney	Strongest Families Institute\L'Institut des Familles Solides
Donald Addington	University of Calgary, Psychiatry
Nora Spinks	Vanier Institute\L'Institut Vanier de la Famille



Mental Health  
Commission  
of Canada

Commission de  
la santé mentale  
du Canada



## Mental Health Commission of Canada

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

Tel: 613.683.3755  
Fax: 613.798.2989

[info@mentalhealthcommission.ca](mailto:info@mentalhealthcommission.ca)  
[www.mentalhealthcommission.ca](http://www.mentalhealthcommission.ca)

[@MHCC](https://twitter.com/MHCC) [f/theMHCC](https://www.facebook.com/theMHCC) [▶/1MHCC](https://www.youtube.com/channel/UC1MHCC) [@theMHCC](https://www.instagram.com/theMHCC)  
[in/Mental Health Commission of Canada](https://www.linkedin.com/company/mental-health-commission-of-canada)