# Chapter 4 Key Findings by Goal

This chapter presents a synthesis of key findings from the Regional Dialogues and the Online Consultation for each of the goals outlined in the draft document *Toward Recovery and Well-Being: A Framework for a Mental Health Strategy for Canada.* 

Qualitative feedback on each of the draft goals was collected through participants' comments across all Regional Dialogues; open-ended questions posed to public participants and stakeholders in the online workbooks; stories and ideas submitted online by public participants; and stakeholders' comments and written submissions, received through the Online Consultation website.

In addition, a series of close-ended questions on each of the draft goals was posed in the public and stakeholder online workbooks and a summary of the resulting quantitative data is included in the discussion that follows. More detailed supporting data tables are also provided in Appendices 4 and 5 for reference. Given the very high volume of comments received, qualitative analysis working tables have not been appended but are available upon request to the Mental Health Commission of Canada.

Working sequentially goal by goal, we present here an integration of qualitative and quantitative results, with emphasis on the most frequently recurring themes across all of the above data sets. Also included, where pertinent (and when available), are some of the personal stories shared by participants.

As noted in Chapter 3, the congruence in results across qualitative and quantitative feedback, and across the in-person and online consultation streams, is striking. While there are nuanced differences in perspectives on some issues – in particular regarding the role of families with respect to recovery, prevention and promotion – the overall messages heard for each goal, and for the 8 goals taken together, is extremely consistent. Therefore comparisons between the online and in-person consultations are only noted when significant.

It is important to note that the majority of online participants, particularly members of the public participating online, provided their input based on an "abridged" version of the Framework document (i.e., the online workbook). Similarly, some (although not a majority) of Regional Dialogue participants had only reviewed the Framework's Summary of Goals and/or its short-form goal statements. As a result, some of the frequently mentioned comments and suggestions that follow pertain to issues that were in fact included in the full version of the Framework. Notwithstanding, this does highlight the importance of ensuring that these areas of concern be addressed explicitly and "up front" in the revised Framework document.



### Goal 1: The Hope of Recovery is Available to All

#### What we heard...

#### Freedom

My perspective: Person living with a mental health problem/illness

I am a 25 year old trauma survivor. Throughout my life as young as 13 I have engaged in substance abuse, self-harm and was bulimic, depressed and suffering from posttraumatic stress for 11 years of my life. Not a day went by that I did not think about suicide, I even attempted to take my own life at age 16. Thankfully, I survived. THERE IS HOPE. No matter what the statistics look like, or what any "DR" says to you...there is always HOPE.

I have come from the very bottom and the lowest of lows...up to the happiest most productive person I have ever been in my entire life. I fought every step of the way to survive through mental illness and addiction. I didn't always know how I would make it through to the next day, but deep down inside of me I never gave up on HOPE.

Now I am a Social Worker student and my dream is to spread the hope of recovery. Sometimes the "DR's" "treatment plans" don't work, they are not individualized and tailored to suit everyone's unique situations and unique personalities...so I made my OWN treatment plans. I took my treatment into my own hands, and did what worked best for me and kept myself safe... and through this...I am in recovery.

The hospitals and doctors THINK they know what's best...but let's always remember...WE KNOW WHAT IS BEST FOR US!! We know ourselves better then they do...they MAY have a degree in psychiatry or psychology...but we are HUMAN BEINGS..NOT DISEASES TO BE TREATED. Recovery is beautiful. It is the most wonderful place in the world to be...living inside my own skin has never felt so good. Take responsibility for your recovery...educate and empower yourself..it is the only way to freedom. "Hope is the companion of power, and the mother of success; for who so hopes has within him the gift of miracles."



#### What we heard...

#### **Choosing Sanity**

My perspective: Advocate

My name is Margaret Trudeau-Kemper. For thirty years of my adult life I suffered the debilitating effects of my bi-polar condition. I had been unable to accept that I truly was suffering a mental illness. The stigma, my ignorance led me to believe that it was just natural for me to have highs and lows. I suffered post-partum depression after the birth of my second child. My mood swings: the unabashed highs, and so lonely lows were noticed. I received treatment but research was not yet producing the results that would define my chemical imbalance.

I had my first of three hospitalizations in 1974. My last hospitalization was in 2000. I finally accepted that I was very ill and needed help. I did get excellent help from a team of Canadian mental health-care workers... my wonderful Psychiatrists, the compassionate psychiatric nurses, the social workers, the nutritionist. They all got me back onto my feet. I cannot but be grateful for the superb, strong guidance I was given on how I was going to live the rest of my life.

It was a long, slow process. It took years, not days. My doctor complimented me on being "compliant"... I took my medication. (An awful lot, as I recall). I changed my lifestyle. I started watching what I ate from the point of view of feeding the best fuel I could to my jet-propelled mind. My doctor recommended I take Vitamin B's, Omega fish oil, and folic acid in addition to any prescribed meds. Those I take daily. I call them brain supplements. They work together to refresh and fine-tune the transmitters in my brain that control my huge range of emotions.

The best gift choosing sanity and asking for help gave me is emotional intelligence. I exercise in healthy moderation. I guard my hours of sleep jealously. Sleeping heals an unquiet mind. I self-monitor, instead of self-medicate. After years of psycho-therapy, I know who I am. I know my limits. When I feel myself losing balance I quickly go into repair mode: good food, good exercise, good play, good sleep. I try hard to live in the moment, I leave the horrors of my past behind, I fret not about the future.

*I am now a happy, whole, contributing person, thanks to our mental health care system.* 

*Presently I public speak on mental health issues and am writing a book. I sit on the board of the U.B.C. Mental Health Institute. Thank you. MT* 

Much of participants' feedback on Goal 1 focused on the following themes:

Recovery should be actively expected, promoted, encouraged and supported to all individuals with mental health issues from the time of diagnosis. This not only instills hope to the individual, but also their families. It is much easier to foster and encourage hope before it is lost than it is to rebuild it once it has been lost.

> Online Participant Ontario

- Hope and recovery are central drivers for transforming the mental health system.
- Person-centred and holistic approaches are fundamental to recovery and should include the concept of selfdetermination.
- The role of "communities" in supporting recovery must be elevated, while recognizing their complexity and diversity.
- 4. Mental health service providers are key partners in the recovery process, and as such, must integrate a recovery focus into their practices.

#### 1.1 Hope and recovery are central drivers for transforming the mental health system

Participants were generally very positive about the power and potential of the concepts of hope and

recovery, seeing them as pivotal to the achievement of a truly transformed mental health system in Canada. In fact, some suggested that these concepts should be woven more systematically within all of the Framework goals.

Hope ignites action and moving towards recovery...

Regional Dialogue Participant Regina, Saskatchewan

Strengthen the idea that recovery doesn't have to mean a cure but being able to live a meaningful life; this won't be as overwhelming to individuals with a mental illness because they're not expected to "cure" their illness but gives them hope for a better life.

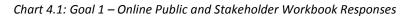
> Online Participant Prince Edward Island

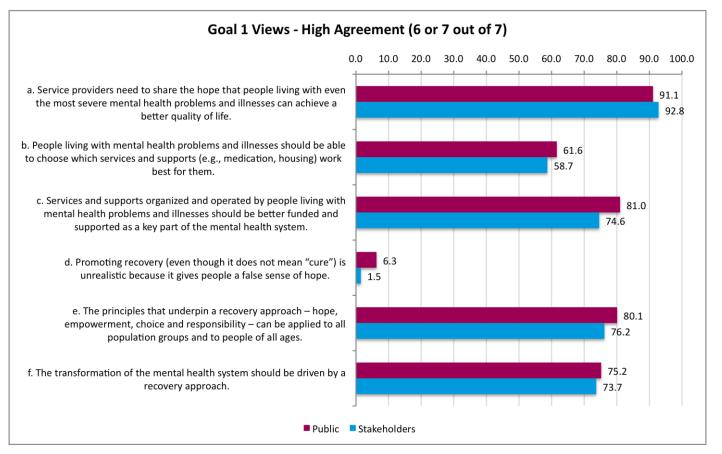
However, a large number of participants also felt that the Commission must define these terms more clearly, to avoid confusion about their intended meaning and to ensure that they are well understood by all Canadians. In particular, many were concerned that the term "recovery" might be misinterpreted by the general public as meaning "cure". More broadly, participants spoke to the importance of "mental health literacy", particularly as it relates to the intended meanings of hope and recovery. A number of participants noted that more needs to be done to adapt the term "recovery" and its use, so as to give it appropriate meaning for specific populations such as children and youth, seniors, and First Nations, Inuit and Métis. Others, while recognizing the merit of the concepts of hope and recovery, cautioned that unless the necessary services, supports and opportunities are available and accessible, focusing on these terms poses the risk of creating unrealistic expectations. Finally, many others spoke about the need for this goal to take into account social determinants of health.

[It is] difficult to consider recovery without making reference to social determinants of health.

Regional Dialogue Participant Thunder Bay, Ontario

Online public and stakeholder workbook responses (see Chart 4.1, below) on related questions confirm strong overall support for the principles underlying the concept of recovery (see Chart 4.1 - d, e) and for a recovery-oriented mental health system (see Chart 4.1 - f). Participants also believed that service providers need to share the hope that all people can achieve a better quality of life (see Chart 4.1 - a); persons with mental health problems or illnesses should be able to choose which supports or services work best for them (see Chart 4.1 - b); and services and supports operated by people living with mental health problems and illnesses should be a key part of the mental health system (see Chart 4.1 - c).





## **1.2** Person-centred and holistic approaches are fundamental to recovery and should include the concept of self-determination

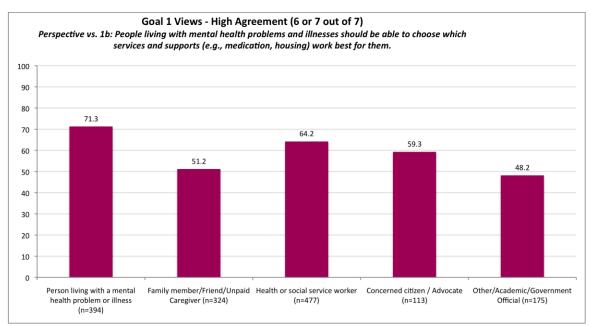
Treating the person as a whole person – this requires working together as a team with other health service providers, but also with families – this...important shift has to happen.

> Regional Dialogue Participant Edmonton, Alberta

A recurring message emerging across discussions and comments about the notion of "recovery" was the importance of embracing a very holistic and personcentred approach that reflects all four dimensions of one's overall health: physical, mental, emotional and spiritual. It was noted by participants that the draft Framework had not adequately included the emotional and spiritual dimensions.

Discussions during the in-person sessions also frequently focused on another aspect of person-centred approaches: the concept of self-determination and its corollary, the notion of "informed choice". To truly exercise self-determination, participants noted, people need to be well informed of and understand the options available to them so that they can make responsible choices.

In their workbook responses, close to 60% of stakeholders and just over 60% of public respondents agreed that *"people living with mental health problems and illnesses should be able to choose which services and supports (e.g., medication, housing) work best for them"* (see Chart 4.1 – b). However, among public respondents, persons living with mental health problems and illnesses expressed the highest level of agreement with this statement (71%), followed by health or social service workers (64%). As illustrated in Chart 4.2 below, family members/friends/unpaid caregivers were in much lesser agreement (51%).





Finally, participants expressed high support for the notion that services and supports operated by people living with mental health problems and illnesses should be a key part of the mental health system (see Chart 4.1 - c).

## **1.3** The role of "communities" in supporting recovery must be elevated, while recognizing their complexity and diversity

While the draft Framework speaks of "community" in the singular, participants clearly directed the Commission to adopt the plural form of the term, both literally and philosophically. Pointing out that "community is a complex concept", participants were insistent that each individual might belong to a number of different communities, including communities of interest, geographic communities, and social movements. They also referred to the need to recognize the reciprocal nature of the relationship between communities and people with mental health problems and illness: each gives and receives something unique in turn.

One size doesn't fit all – we have to work with communities to understand their needs and develop programs and services that fit: person-centred and community centred – this links with the cultural safety goal.

> Regional Dialogue Participant Yellowknife, North West Territories

Participants also frequently emphasized that community well-being and mental health well-being are intimately interconnected. To paraphrase one online participant: *"strengthen community well-being, as community supports and programs are the primary resource for those with little or no family support."* Building on this notion, many noted that regardless of – and often due to – their diversity, communities play an important part in supporting recovery, in fostering mental health and in preventing mental health problems and illnesses.

Finally, participants called attention to the very significant discrepancies within and among geographic communities in regard to the availability of programs, services, and supports. This was noted as a point requiring greater emphasis in the Framework document, particularly with respect to the very unique needs of Northern and remote communities.

## **1.4** Mental health service providers are key partners in the recovery process, and as such, must integrate a recovery focus into their practices

Mental health service providers (MHSPs) in all their diversity, and including peer workers and informal caregivers, were seen to have an enormous impact on the lives of people with mental health problems and illnesses. As such, participants believed they are ideally positioned to promote and deliver recovery-oriented services.

Online workbook responses strongly support this point – over 90% of online public and stakeholder respondents believe that *"service providers need to share the hope that people living with mental health problems and illnesses can achieve a better quality of life."* (See Chart 4.1 - a).

However, participants also noted that in order to successfully do this, MHSPs must be appropriately trained in recovery-oriented approaches, and must benefit from greater supports. Going further, some suggested that the Framework should acknowledge that MHSPs will need in some cases to re-align their practices to reflect a recovery focus.

### Goal 2: Action is taken to Promote Mental Health and Well-Being and to Prevent Mental Health Problems and Illnesses

#### What we heard...

#### Prevention at an early age

My perspective: Friend of a person living with a mental health problem/illness

We have a friend with mental problems and a relative. Both are single males now in their 30s and 40s. We feel that if they had received therapy and guidance as young teenagers, their problems might have been resolved or avoided altogether and the pensions they now receive from the government might have been saved. Moreover, both might have become active, useful members of society contributing to society's success.

Our suggestion: Check on children and teens while at school and if there are certain symptoms, provide them with psychiatric evaluation and care [...]. Early detection and early remedies may salvage quite a few lives.



#### What we heard...

#### Does our current society foster good mental health?

My perspective: Concerned citizen

I fully support your plan. Personally, when I read that current/projected mental illness statistics for Canadians and citizens of partner G8 nations are so high as to warrant the creation of nationalized mental health strategies – I think this crisis also warrants a closer look at our societies.

In my opinion, any Mental Health Strategy for Canada should include tandem representation from the business, public service, and other sectors: thoughtful company leaders/employers, urban planners and developers, essential service providers, high tech leaders – those at the forefront of creating societal structures and systems in which Canadians live and work and who are influencing the ways we interact with one another.

I believe these sectors should be working with a meaningful spectrum of health experts to evaluate our communities, institutions, companies and our larger Canadian society against the benchmarks of known factors that promote mental and physical health and known risks to mental and physical health and well-being.

I'd also like to see a national discussion among all Canadians about what general life/work/community styles we as Canadians would like to live. I'd hope that these initiatives would lead to more thoughtful planning and more public engagement in creating and supporting more sustainably healthy working and living environments.

If we don't address the readily observable and frequently reported escalating isolation, frustration, and stress experienced by so many members of our society - from the very young to the young at heart, I think we can expect to see the number of fellow citizens affected by mental illness to continue to climb. It seems to me that we'll then be on an very unmerry-go-round - helping affected individuals to enter or re-enter living and working environments and a society that seems, to me and perhaps others, to be filled with too many of the very factors known to trigger poor mental health, mental illness and disorders. And round again we go.

I do not think that national or global economic and human needs are irreconcilable. For the benefit of all Canadians and with a view to becoming a global leader on this issue – I think we should welcome every sector and every citizen aboard this initiative and together, we should strive to achieve this.



The following key themes arose from participants' feedback on Goal 2:

- Mental health promotion and mental illness prevention must be an integral part of the Framework.
- 2. The critical role of social determinants of health (SDH) in mental health promotion and mental illness prevention merits greater recognition throughout the Framework.
- 3. Emphasize that the education system and health human resources training play a key role in raising awareness about mental health promotion and mental illness prevention, and in supporting early identification and intervention.
- **4.** This goal should demonstrate the effectiveness of prevention and promotion strategies by highlighting pertinent research and more compelling examples.
- 5. Prevention and promotion will require much greater coordination and collaboration across all sectors and spheres.

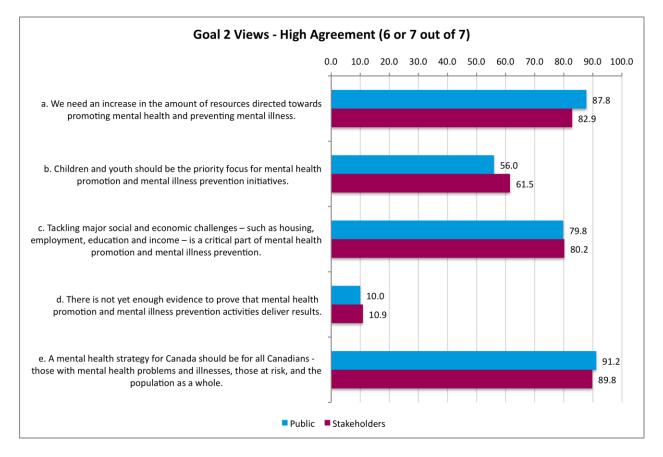
## 2.1 Mental health promotion and mental illness prevention must be an integral part of the Framework

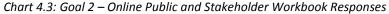
Participants expressed a high level of support for positioning prevention and promotion as equally important pillars within the Framework's foundation. However, many also suggested that the Framework include and place greater emphasis on the importance and role of "resilience" in prevention and promotion. Others added that our understanding of "resilience" must also include cultural and traditional values and the role they play in strengthening identity – thus being instrumental in promoting mental health.

Participants' recognition of the pivotal importance of prevention was, however, tempered by an important caveat: without denying the power of prevention and treatment, many cautioned that the Framework must not suggest or state that all mental illnesses can be prevented or cured.

Online participants clearly echo these views (see Chart 4.3, below):

- Public and stakeholder respondents expressed strong support for the need to target more resources towards promotion and prevention (see Chart 4.3 – a), reflecting the belief that promotion and prevention delivers results (see Chart 4.3 – d).
- While they believed that a focus on children and youth was important (see Chart 4.3 b), participants where overwhelmingly in agreement that a mental health strategy for Canada should be for all Canadians (see Chart 4.3 – e).
- Tackling major social and economic challenges (i.e., social determinants of health) were seen as a critical part of promotion and prevention (see Chart 4.3 c).





#### 2.2 The critical role of social determinants of health (SDH) in promotion and prevention merits greater recognition throughout the Framework

L'importance d'intervenir sur les facteurs socioéconomiques – c'est dans le texte mais pas assez clair/fort dans l'énoncé et le 1er paragraphe.

> Regional Dialogue Participant Montreal, Quebec

Participant feedback gave a prominent place to the positive and negative roles of social determinants of health in the area of mental health promotion and mental illness prevention: social determinants of health can be a contributing cause of mental health problems and illnesses, as well as a protective factor in its prevention and the promotion of mental health. The view that people's basic needs must be taken care of – food security, housing, income, etc. – was heard and written repeatedly. This concern is echoed by public and stakeholder respondents' workbook responses: as illustrated in Chart 4.3 – a), approximately 8 out of 10 online public and stakeholder respondents expressed high agreement with the notion that *"Tackling major social and economic challenges – such as housing, employment, education and income – is a critical part of mental health promotion and mental illness prevention."* 

# 2.3 Emphasize that the education system and health human resources training play a key role in raising awareness about mental health promotion and mental illness prevention, and in supporting early identification and intervention

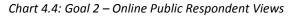
Including the full continuum from kindergarten to postsecondary education, participants emphasized the role of education institutions in raising awareness among students and parents about mental health issues. To be effective, they stated, educators of all stripes need to be much better informed and equipped to identify and deal with mental health issues. This was seen to be especially important in supporting an early diagnosis and intervention strategy for children and youth.

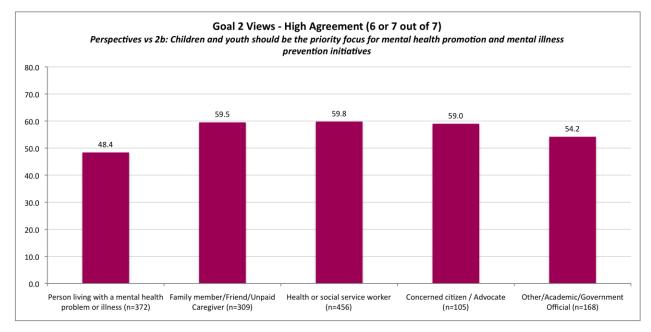
Since most mental illness develops in childhood and adolescence, I think that people who work with these young people (teachers, parents etc.) should be well educated in recognizing the early signs, know where to go to get more information and reach out for help in order to help. From what I've seen and experienced teens won't reach out for help alone and they do not receive help until they end up in emergency in crisis. Reaching out for help should be easy and accessible for young people.

Online Participant Ontario

Turning to the quantitative results for several related questions, one sees that while a majority of respondents (62% of stakeholders and 56% of public respondents) believed that a focus on children and youth was important (see Chart 4.3 - b), participants where overwhelmingly in agreement that a mental health strategy for Canada should be for all Canadians (see Chart 4.3 - b, e).

However, it is noteworthy that only 48% of persons living with a mental health problem or illness expressed high agreement with the statement *"Children and youth should be the priority focus for mental health promotion and mental illness prevention initiatives"* – compared to roughly 60% of families/friends/unpaid caregivers, health or social service workers, and concerned citizens/advocates (see Chart 4.4).



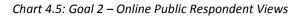


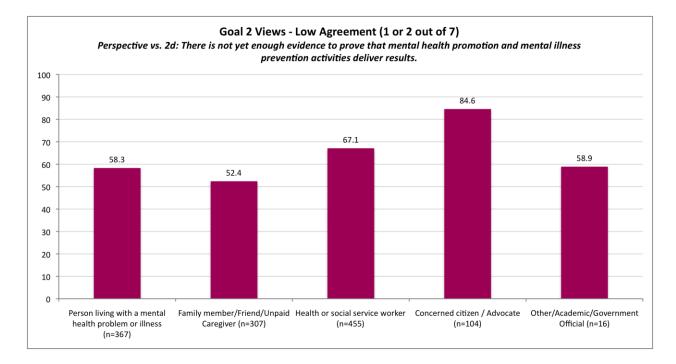
## 2.4 This goal should demonstrate the effectiveness of prevention and promotion strategies by highlighting pertinent research and more compelling examples.

There was a sense that the Framework could do more to illuminate existing research from Canada and abroad that demonstrates the effectiveness of prevention and promotion strategies. In addition, the Commission was advised to take an inclusive approach to evidence: drawing from diverse types and sources of knowledge, incorporating learning from "promising" as well as best practices, and tapping into experiential evidence.

In looking at the examples the Framework supplied to describe factors that increase the risk of mental health problems and illness, many participants urged the Commission to either replace or supplement the examples provided (e.g., bullying) with more compelling and serious examples, i.e., sexual, emotional and physical abuse.

The fact that roughly 90% of participants disagreed with the statement *"there is not enough evidence to prove that mental health promotion and mental illness prevention activities deliver results"* (see Chart 4.3 – d) strongly corroborates participants' comments on this topic. This view was held particularly strongly by members of the general public/advocates, 85% of which were in disagreement with this statement (compared to 52% of family members/friends/unpaid caregivers and 58% of persons living with a mental health problem or illness). (See chart 4.5).





## 2.5 Prevention and promotion will require much greater coordination and collaboration across all sectors and spheres

Participants felt that the Framework must more clearly and strongly articulate the scope of change required to break down vertical, silo-like practices and move to a whole-system, integrated approach. In particular, they spoke of the need to bring together the wide range of policy and service sectors (e.g., health, education, social, criminal justice and others) – across the public, private, and voluntary/community spheres – that must play a role in addressing mental health issues.

### Goal 3: The Mental Health System is Culturally Safe, and Responds to the Diverse Needs of Canadians

With regards to Goal 3, participants expressed the following views:

We are talking about values, beliefs, biases, how we see each other, relationships, what we bring to the table...it's about listening to the individual and finding out what their belief system is all about, hearing what they are saying...

Regional Dialogue Participant Halifax, Nova Scotia

- The concepts underlying "cultural safety" are important and should be included in the Framework, but the term's accessibility and utility as presented in the Framework is cause for concern.
- 2. This goal needs to be more explicit and carefully framed to present the full complexity of cultural safety issues, avoid oversimplification, and maintain the focus on person-centred approaches and practices.
- This goal should further clarify the role and importance of mental health service providers in providing "culturally safe" services and supports.
- 4. First Nations, Inuit and Métis have a unique place in Canada's history and society this goal should recognize their unique histories and status in Canada.

# 3.1 The concepts underlying "cultural safety" are important and should be included in the Framework, but the term's accessibility and utility as presented in the Framework is cause for concern

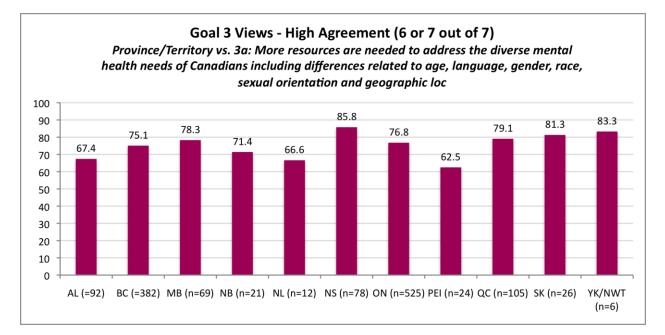
Many participants were exposed to the term "cultural safety" for the first time and expressed some initial discomfort with it, particularly with regards to how the term *could* be interpreted. Once the intended meaning and use of the term was explained, most were supportive of its general thrust and underlying concepts.

Notwithstanding, many believed that the term "cultural safety", if it is to be included in the Framework, requires more careful and clear explanation and definition. Others, albeit a minority, felt that even with greater clarity, its usage might have negative unintended consequences (e.g. raising unattainable expectations about service delivery in hundreds of languages; accepting certain ethno-cultural views on mental illnesses that may jeopardize diagnosis and intervention).

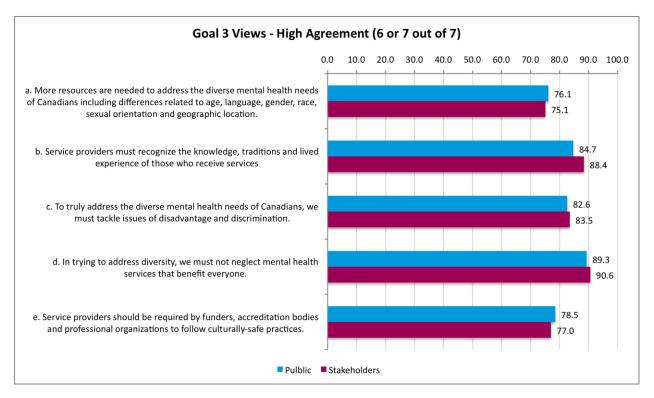
[Le terme] pourrait être interprété de façons diverses et mener à des décisions qui pourraient aller à l'encontre d'un cheminement de rétablissement Regional Dialogue Participant Montreal, Quebec Looking at the quantitative online results, online public respondents broadly agreed that "to truly address the diverse mental health needs of Canadians, we must tackle issues of disadvantage and discrimination". (See Chart 4.7 - c).

One also finds strong agreement with the notion that *"more resources are needed to address the diverse mental health needs of Canadians including differences related to age, language, gender, race, sexual orientation and geographic location"* (see Chart 4.7 – a). Furthermore, there were no marked differences in agreement with this statement among the various respondent groups, whether by perspective, age group, rural and urban dwellers, Aboriginal and non-Aboriginal heritage, Francophones and Anglophones, and length of residency in Canada. Agreement with this statement varied across provinces and territories, however, ranging from 63% in P.E.I. to 86% in Nova Scotia. (See Chart 4.6, below).





Are we going to be obliged to offer services in every minority language that makes its way to Canada? Are we going to accept every ethnoracial definition of mental illness which may not be considered a mental illness in Canada, because it would be not politically correct of us to contradict someone else's cultural tradition? Online Participant British Columbia However, participants also believed that "in trying to address diversity, we must not neglect mental health services that benefit everyone" (see Chart 4.7 - d) – a clear caution to be careful not to neglect the needs of the many in order to meet those of the few. This cautionary theme is evident across both qualitative and quantitative streams and perhaps even more pronounced in the Online Consultation results.



#### Chart 4.7: Goal 3 – Online Public and Stakeholder Workbook Responses

# 3.2 This goal needs to be more explicit and carefully framed to present the full complexity of cultural safety issues, avoid over-simplification, and maintain the focus on person-centred approaches and practices

Participants noted that ethno-cultural/racial concepts and realities are highly complex, involving multiple and varied factors, including self-identity, gender, sexual orientation, historical context, power relations etc., that need to be taken into consideration.

We need an intersectional lens (from a feminist perspective): how do all the variables intersect from the perspective of this one individual, and what is the impact of this intersection on this individual (we need to have a whole person view, avoid labeling)

Regional Dialogue Participant Edmonton, Alberta We are attempting to understand culture in all its multiplicities – rather than listening to people – to what they are telling you and what they are trying to say in a shielded and less filtered way ... listen to the person, not the culture...There is a danger of saying culturally diverse, safe, competent but stereotyping may result and this may not be productive – particularly with evolving cultures and communities – caution is in order.

Regional Dialogue Participant Toronto, Ontario

## 3.3 This goal should further clarify the role and importance of mental health service providers in providing "culturally safe" services and supports

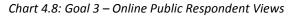
I do not think there is enough emphasis on the cultural competency in providing culturally sensitive mental health services in Canada. There needs to be more support for multicultural training of mental health service providers.

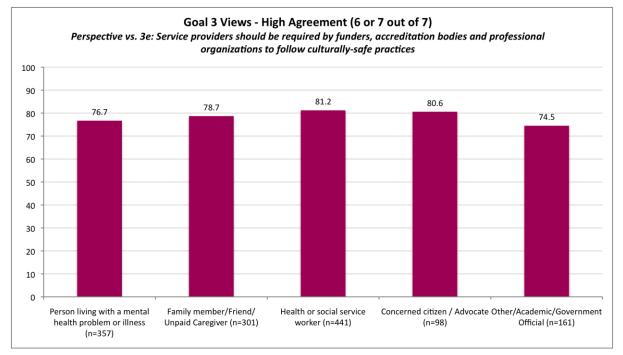
> Online Participant Alberta

Given that mental health service providers are on the front lines of mental health delivery, participants believed that they are well positioned to play critical roles in providing culturally safe and competent services. However, many underscored that for this to be the case, health workers must be provided with focused cultural competence training, supports and tools. Others noted that Canada lacks culturally diverse mental health service providers to serve Canada's diverse population.

Looking at online participants' views on the role of service providers vis-à-vis cultural safety, one finds a clear expectation that service providers *"recognize the knowledge, traditions and lived experience"* of their clients (see Chart 4.7 - b).

In the same vein, there was also high support for the idea that funders, accreditation bodies and professional organizations require that service providers follow culturally-safe practices (see Chart 4.7 – b, e). Agreement with this statement was fairly consistent across all perspectives. However, it is worth noting that although the margin was slight, health or social service workers showed the highest level of agreement with this statement (81%). (See Chart 4.8).





#### 3.4 First Nations, Inuit and Métis have a unique place in Canada's history and society – this goal should recognize their unique histories and status in Canada

Cultural differences need to be recognized for First Nation, Inuit and Métis to advance.

Regional Dialogue Participant Thunder Bay, Ontario Many worried about the impact of including First Nation, Inuit and Métis populations among other ethno-cultural/racial groups in the Framework. They argued that Aboriginal peoples should be addressed separately, in recognition of their unique place in Canada's history and society; their critical and urgent needs with respect to mental health issues; their historical and ongoing suffering; and power imbalances. Some advocated adding a new goal specific to these populations, whereas others preferred to have First Nation, Inuit and Métis needs integrated within each of the 8 goals.

It should be noted that this point emerged in a majority of Regional Dialogue sessions and in all three Territorial locations, but did not surface explicitly in the Online Consultations. This could be due to the fact that Aboriginal participation in the Online Public Consultation was fairly low (5%), and because the online workbook did not specifically link cultural safety to First Nation, Inuit or Métis issues.



### Goal 4: The Importance of Families in Promoting Recovery and Well-Being is Recognized and Their Needs are Supported

#### What we heard...

#### Families need more involvement in treatment/programs

My perspective: Health or social service worker

My experience as the sister of someone with a mental health illness is that, although I have been a resource person and support to my sister for years, I was not included in the treatment and recovery process.

While my sister was in a 3 month program, I was not able to participate. I had to rely on my sister to tell me what was happening in the program, and there were no resources for me to understand how to better support her. As a result, I felt like I couldn't voice my concerns, didn't understand the treatment, and wasn't able to support her as well in her recovery process as I could have.

I was also very disappointed and frightened by the lack of support available for my sister once she was discharged from the program. She was discharged as soon as she had met the program goals, but without any ongoing support or resources to help her continue healing at home, or any resources for us as family members to help her. Within a week, almost all of the work done while she was in the program was undone. Her physical health suffered to the degree that I was afraid for her life. My mother's attempts to get help from the program were rebuffed, because my sister was no longer a participant. It was clear that the program had no further concern for her once she was not their patient.

At the same time, this was a terrifying, stressful and emotional experience for me and my family. I had no support to help me deal with trying to work full-time while worrying about my sister's mental and physical health and attempting to provide her with any support I could. In the end I feel the only way I was able to deal with it was to distance myself from my sister, which I feel very guilty about. It also placed more of a burden on my parents and my sister's partner.

I wish there had been resources to help me deal with what was one of the worst times of my life. It would have been helpful if that help had been linked to the program that my sister was in, so that the people would know what my sister and my family were going through, since that could impact what kind of care and resources they could provide. I strongly support your goal of involving and supporting families. Thank you for the work you are doing!!



#### What we heard...

#### Involve the families in treatment

My older brother has been involved in the mental-health system periodically for over 30 years. He has schizophrenia. When his symptoms get really bad, we try to reason with him to seek help from a doctor or from the psychiatric hospital, but when he is sick, there is no reasoning with him. We call the hospital, but they can't tell us anything. They can't tell us when (or even if) he is scheduled to visit their outpatient clinic, as it is a privacy issue.

As for getting him help, unless he agrees to go voluntarily, we must wait until something serious happens and then call the police. Last year the Province introduced a new mental-health act, with the promise of community outreach teams. However, to date we see no change in the system.

As family, we are not my brother's enemy. But we are treated as strangers, since he has no wife or children. It is frustrating to see him spiral into the depths and not be able to take any action except to stand by and watch till he crashes. He is in his late 40s now, and our mother is in her late 70s (our father passed away a decade ago). His syptoms recur more frequently, and he is losing every place where he rents accommodations, as he more or less destroys each place with filth and cigarette butts. The situation grows worse each year and there are no good solutions in the system.

Thanks for reading these comments. We particpated in the provincial review of the mental-health act (made a submission and attended meetings), but nothing has changed to date.

Goal 4 elicited the following feedback from participants:

[We] need to achieve greater balance between individual and family; recognition that it is not a black and white equation.

> Regional Dialogue Participant Halifax, Nova Scotia

- This goal must more fully reflect efforts to balance the individual's right to choice, privacy and consent with families' need for information and their potential contribution to the individual's recovery.
- More clarity is required about the right of individuals to determine who is included in their "family" and the extent to which their designated family is involved in their care.
- More emphasis is required on the needs of families particularly caregiving families – for services and supports, including financial supports and respite care.
- 4. A more inclusive definition of "family" should be provided early on in the Framework and included within this goal.

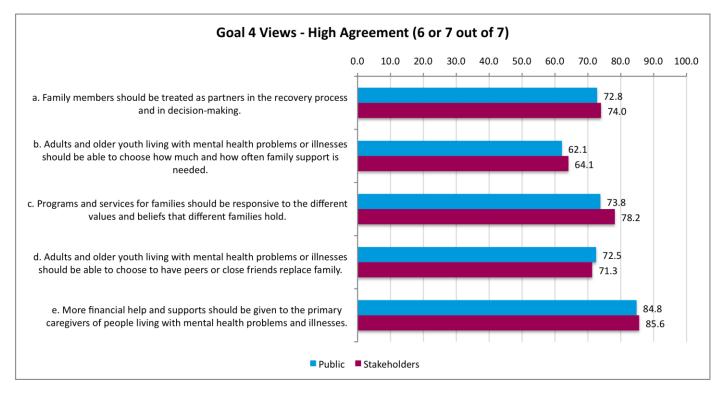
#### 4.1 This goal must more fully reflect efforts to balance the individual's right to choice, privacy and consent with families' need for information and their potential contribution to the individual's recovery

I think more emphasis needs to be placed on the fine balance between respecting the care giving role of the family while not undermining the autonomy of the individual. Of course, this is likely clearer cut when [...] individuals are deemed competent to give consent.

> Online Participant British Columbia

Notwithstanding different views with respect to the role of families within mental health systems, participants expressed clear support for confidentiality and consent as key underpinnings for a person-centred transformed mental health system. The question of finding the right balance between the individual's right to privacy, choice and consent and the family's need for information and desire to be involved was widely acknowledged as one of the most divisive issues within the mental health community – one that has embedded tensions that are not fully reconcilable.

Online public responses strongly echoed this view, with respondents expressing fairly balanced agreement with the need to respect both the needs of families (see Chart 4.9 – a, c, below) and those of persons living with mental health problems or illnesses (see Chart 4.9 – b, d). There was also agreement across public and stakeholder participants that *"programs and services for families should be responsive to the different values and beliefs that different families hold"* (see Chart 4.9 – c).



#### Chart 4.9: Goal 4 – Online Public and Stakeholder Workbook Responses

# 4.2 More clarity is required about the right of individuals to determine who is included in their "family" and the extent to which their designated family is involved in their care

While many saw families playing – for the most part – a positive role in promotion, prevention and treatment, participants felt strongly that this goal should also reflect the fact that families can and do also contribute to risk factors for mental health problems and illnesses. In general, the view articulated was that the Framework did not adequately address the following points: not all families are beneficial; not all people have families/peer support; and some families are unable or unwilling to play a significant role in the lives of their family member with mental health problems or illnesses.

I am not sure we want to make family members partners in every circumstance. There is no doubt that they can be essential partners, but they also can be very toxic and a primary source of stress.

way to recovery and are placed back into dysfunctional family situations which destroy what has been achieved.

Sometimes children are well on their

Online Participant Ontario

Online Participant Alberta Participants suggested that all those involved in the support or treatment of persons living with mental health problems or illnesses must demonstrate sensitivity and exercise good judgment in dealing with matters relating to personal privacy, the right to choose, and the role of families/circles of care. They also clearly recognized the complexity of the legal, social and ethical issues that typically arise in such cases. Notwithstanding, they strongly believed that mental health professionals can – and should – be proactive and supportive of families, without breaching client confidentiality or requirements of the law.

I think there should be more emphasis on the fact that anyone over the age of 16 has the choice whether to involve their family or not and how much they want to involve them, it should never be forced. Also confidentiality between the person suffering from mental illness and their mental health professional should be kept.

> Online Participant Ontario

On this topic, online participants' responses to the statement *"family members should be treated as partners in the recovery process and decision-making"* revealed interesting results. While 90% of those identifying as family members/friend/unpaid caregiver strongly agreed with this statement (see Chart 4.10, below), only 62% of people living with a mental health problem or illness agreed. Agreement with this statement also tended to increase with age (approximately two-thirds of those 15-24 agreed versus roughly three-quarters of those in the 45-54, 55-64 and 65-74 age categories).

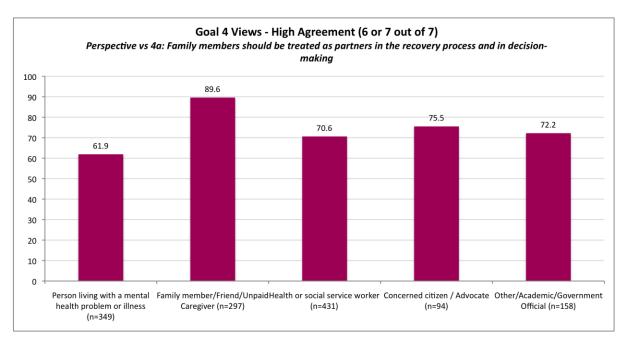


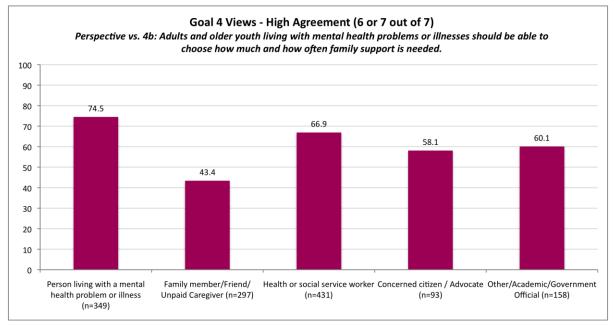
Chart 4.10: Goal 4 - Online Public Respondent Views



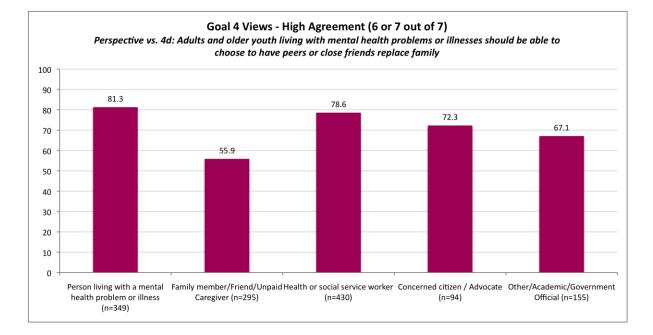
Responses to the statement *"adults and older youth living with mental health problems or illnesses should be able to choose how much and how often family support is needed"* (see Chart 4.9 – b) are also noteworthy.

A majority – 62% of public respondents and 64% of stakeholders – were in agreement. However, when analyzed by perspective, a clear divergence is apparent: three quarters of people living with a mental health problem or illness strongly agreed with the statement, in contrast with less than half (43%) of families/friends/unpaid caregivers (see Chart 4.11, below).





A similar pattern is found in analyzing responses to the statement "adults and older youth living with mental health problems or illnesses should be able to choose to have peers or close friends replace family" (see Chart 4.9 – d). While over 50% of respondents in each perspective group were in agreement with this statement, a wide gulf is seen between the views of family members/friends/unpaid caregivers and those of people with lived experience: only 56% of the former agreed with this statement, compared to 81% of the latter. (See Chart 4.12, below).



#### Chart 4.12: Goal 4 – Online Public Respondent Views

#### 4.3 More emphasis is required on the needs of families – particularly caregiving families – for services and supports, including financial supports and respite care

Participants almost unanimously agreed that the Framework should be bolder in advocating for the services and supports required by families – and particularly family caregivers – if they are to be as effective as possible in supporting family members with mental health problems or illnesses. They called for substantially increased resources and supports including: financial supports (in recognition of lost wages and earnings), education on mental health issues, counseling, help with parenting, coaching, respite care, etc. These needs were deemed to be even more acute in Northern, remote and rural areas.

I need support but there is not much there...We need respite care...more group homes, educational help...despite the fact that we are isolated, [we] have fewer resources.

Regional Dialogue Participant Yellowknife, North West Territories Furthermore, participants warned that unless adequate family services and supports are made available, the societal costs of mental illness will increase as family members struggle through burn out and experience their own mental health stresses.

Personally my family has been a huge support through my illness and recovery. As someone who had acute psychosis my family witnessed me being very ill. This was a very traumatic experience for them and one that they still struggle with dealing with emotionally. Support and care for the family is essential and something that was really lacking in my experience. There are needs financial, emotional and physical that the family experiences during a period of sickness and recovery and support for them is really essential because it is them that are supporting us.

Online Participant British Columbia

Online participants were also strongly in support of providing more financial help and supports for primary caregivers – 85% of both public and stakeholder respondents were in agreement with this position (see Chart 4.9 – e). Agreement with this position was also consistent across income brackets.

#### 4.4 A more inclusive definition of "family" should be provided early on in the Framework and included within this goal

I would like to see something here around "family of choice". Sometimes biological family might not be the best person(s) to be in this role and the adult would prefer someone they acknowledge as family in the role. The Mental Health system should respect that decision.

> Online Participant New Brunswick

There was broad agreement that the Framework and the family goal should be inclusive, and acknowledge the full diversity of family configurations and understandings (e.g., same sex families, blended families, extended families, families of one's own choosing, etc.). Participants speaking from a First Nation, Inuit or Métis perspective also noted that their understanding of "family" spans extended families that include aunts, uncles, grand-parents, long-time friends, and community.

Suggested alternative words to family included: family of choice, circle of care, circle of support, natural helpers, natural supports, carers.



Goal 5: People of all Ages Have Equitable Access to a System of Appropriate and Effective Programs, Services and Supports that is seamlessly Integrated Around Their Needs

What we heard...

#### How do you put it all back together?

My perspective: Person living with a mental health problem or illness

I am bipolar and have borderline personality traits as well. Pride kept me from seeking help in some form of denial or it would go away on its own. Finally after years of suffering in silence secluding myself from everyone and everything and basically sabotaging my schooling, employment, friendships, financial everything and digging a hole so huge I had no choice but to accept that I needed help.

I saw my Dr. and was put on a waitlist in February of 2007 and finally saw an intake therapist in August and by September I finally saw a psychiatrist to get a diagnosis. Of course by this time I could not function very well on a day to day basis so I could not afford medications or pills.

Trying to get assistance for essentials is almost impossible. The Psychiatrist gives the prescriptions and diagnosis, the therapist loans you his ear and opinions and the HRDC sends you to the provincial government and they send you to a community program and then you just go in circles at a time when you are least able to put in the time, effort and concentration to deal with more problems.

After becoming penniless, jobless, homeless and my beloved cat getting killed I od'd 3 times.

My dad is pretty financially stable and offered to pay for me to take a vacation from life as long as I took my meds and kept my appts. This is the only way I am almost back on my feet again. My dad had to be my social assistance. I have a job again and every day is a struggle but I will never qualify for another loan from not being able to work or access assistance. I will never finish my degree (I have one year left and unmanageable student loan debt), I will forever be underemployed, I will always struggle.

This is Canada's current mental health system. I can't figure it out so if you do please let me know if you do. Now in "recovery" how do you put it all back together?



#### What we heard...

#### My story

My perspective: Family member of a person living with a mental health problem/illness

My daughter is 16 and has Down Syndrome. She was also diagnosed last year with bipolar. From August to February of this year we have been trying to get help for her. Finally in Feb. we admitted her to the hospital where she was first put in the pediatric ward while waiting for a bed in the adolescent psych unit. 3 days later she was admitted. By this time she had been locked in a manic state for 6 months with no treatment. We were beyond exhausted. The process to even get her into hospital was confusing and stressful. Why did we have to wait so long? Now she is on medication but no psychiatrist is actively involved. There aren't any available here and the wait list is 1 year or more. Her medication is being doled out by the psychiatrist in the APAU but only for a short time as she has been discharged. What do we do then? This is such an appalling state of affairs. Our family is now trying to pick up the pieces with no help from any community resources.

#### What we heard...

#### The long road to recovery

My perspective: Person living with a mental health problem or illness

I've struggled with depression, anxiety disorders (social anxiety, panic attacks, PTSD), and eating disorders for most of my life on and off. As a youth, it was hard to get proper support. I saw many professionals, and had unfortunate experiences with lack of services to help me, especially during a crisis. As an adult I've experienced similar things. The country does not have proper programs, especially for trauma issues or eating disorders. I have struggled to keep myself stable for years, at times feeling like I only have myself to blame, but realizing it is not my fault. I'm still waiting for better programs to come along, not just for myself, but for those who will be struggling in the years to come. My hope is that more will be put in place to help people achieve longer periods of recovery. Without more support and specialized programs, I don't know how we can ever expect people to recover. The following themes were recurrent in participants' feedback on Goal 5:

However you look at it, it [Goal 5] is a key goal and should be moved up in the order of goals.

Regional Dialogue Participant **4.** Ottawa, Ontario

- **1.** The ideas included in Goal 5 are absolutely essential to the Framework.
- 2. The goal statement should be revised to include the notion of "timeliness" of access.
- Closing the large gap between current reality and the envisioned future will pose a significant challenge – a serious cause for concern in the eyes of many.
- **4.** This goal must place more emphasis on the need for an expanded array of coordinated, integrated and person-centred services.

#### 5.1 The ideas included in Goal 5 are absolutely essential to the Framework

This goal elicited the highest and most enthusiastic support across in person and online participation. It received the most consistent and highest support across Regional Dialogue and online public and stakeholder audiences (see Chapter 3, Section 3.1).

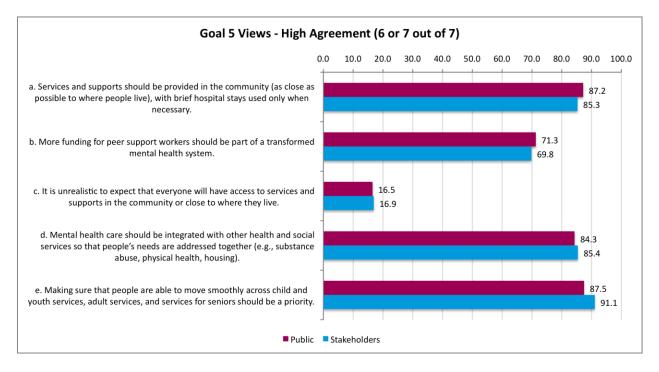
Furthermore, online responses demonstrated strong agreement with the notion that services and supports should be provided in the community (see Chart 4.13 - a, c), that mental care should be integrated with other health and social services (see Chart 4.13 - d), and that people should be able to move seamlessly across services throughout their lifespan (see Chart 4.13 - e).

This is central...there needs to be a range of effective services that cut across, and without this, all the rest falls apart...when you look at this goal from the general public perspective, this could be number 1.

Regional Dialogue Participant Halifax, Nova Scotia

I think that funding for and availability of mental health resources is a huge area where our current system is lacking. There are huge waitlists for essential services, a lack of supported housing for people with mental illness, and inadequate "follow-up" resources in the community to help people once they get out of hospital. There also needs to be more funding for rehabilitation services in the community to help people set and achieve goals to improve their quality of life.

> Online Participant Alberta



#### Chart 4.13: Goal 5 – Online Public and Stakeholder Workbook Responses

#### 5.2 The goal statement should be revised to include the notion of "timeliness" of access

Participants called for the inclusion of a requirement that ensures "timely" access to programs, services, and supports. This, they felt, would be a very important addition to the goal – access which is not "timely", they suggested is purely theoretical. In reality, it denies critically needed services and supports at crucial points in one's recovery journey because of wait times and other such barriers.

People should have access to effective and also TIMELY programs. Long wait times to see, for instance, a counsellor or psychologist is unacceptable. A person who is in desperate need should not have to twist in the wind for weeks to get help.

Online Participant British Columbia



## 5.3 Closing the large gap between current reality and the envisioned future will pose a significant challenge – a serious cause for concern in the eyes of many

First Nation, Inuit and Métis are marginalized and in much worse conditions. We are starting at a total disadvantage and this needs to be reflected. We are trying to catch up to get on an equal footing and then we might get equitable access.

First Nation, Inuit and Métis Dialogue Ottawa, Ontario Participants elaborated on the considerable challenges in moving to implementation, especially with respect to sustainable funding and resources. Many noted that this challenge is particularly acute for First Nation, Inuit and Métis communities; in rural, remote and Northern regions; and among low-income, homeless and other disadvantaged people.

Some also cautioned that stating that having programs, services and supports in one's community or as close as possible to where one lives, while definitely worth striving for, will pose significant challenges in the implementation phase – and may be setting unrealistic expectations.

Notwithstanding, both public and stakeholder online respondents expressed strong support (over 85%) for the notion of having "services and supports in the community (as close as possible to where people live) with brief hospital stays used only where necessary" (see Chart 4.13 – a, c). Public views on how realistic this might prove, however, varied greatly across the country. When asked to what extent they agreed with the statement – *"It is unrealistic to expect that everyone will have access to services and supports in the community or close to where they live" (5c)* – online public respondents from the North unanimously disagreed (100%) compared to roughly half of those from Manitoba (56%), British Columbia (52%) and Ontario (50%) and approximately a third of respondents from P.E.I. (30%) and Newfoundland and Labrador (33%) (see Chart 4.14, below).

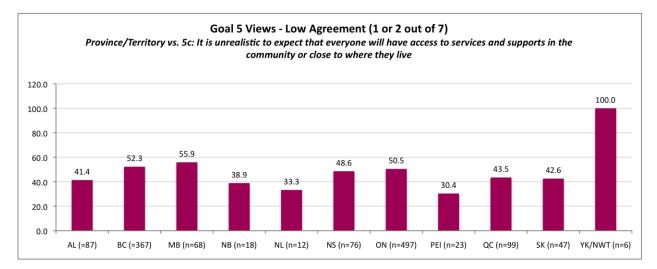


Chart 4.14: Goal 5 - Online Public Respondent Views

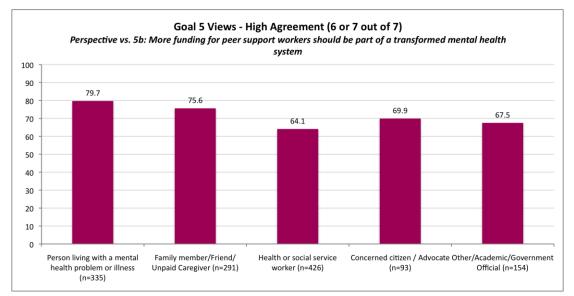


Linked to participants' concern that the Framework more explicitly recognize the implementation gap challenge, participants also advised the Commission to more specifically articulate what success might look like. They felt the Framework could be strengthened – and made more practical – by including references to the types of indicators that could be used to guide progress and monitor success (e.g., performance indicators, desired outcomes, benchmarks). They also highlighted that such indicators would also be required for sub-populations, including youth, seniors, and Aboriginal peoples. Without this, participants worried that it will be difficult to determine whether the mental health strategy is effective in transforming the mental health system in Canada.

Having said this, participants also recognized that the development of performance indicators, outcomes, and evaluation frameworks is challenging and will require additional research – research, they suggested, which must not be restricted to bio-medical factors (participants' comments on research more generally are discussed in Goal 6).

## 5.4 This goal must place more emphasis on the need for an expanded array of coordinated, integrated and person-centred services

Participants felt strongly that this goal should be more forceful in its discussion of the need to integrate mental health and physical health systems services – both formal and informal – including communitybased services and supports, mutual aid and peer supports. For example, online public and stakeholder respondents clearly acknowledged the importance of providing more funding for peer support workers in a transformed mental health system (see Chart 4.13 – b). Perhaps not surprisingly, this view was most strongly held by respondents who identified themselves as persons living with a mental health problem or illness (80%), while those identifying themselves as health or social service workers expressed the lowest level of agreement (64%) with this notion (see Chart 4.15, below).



#### Chart 4.15: Goal 5 - Online Public Respondent Views

Participants also indicated that the goal must have a clearer focus on the need to invest in health human resource planning as a critical component of access, or as one St. John's Regional Dialogue participant put it: *"having the right people, at the right place, at the right time".* 

Finally, participants advocated that the Framework must stress the need for a broader array of mental health workers to be eligible (e.g., psychological services, clinical counseling) for coverage under health plans. Northern and First Nations, Inuit and Métis participants sought to have traditional healers, elders and helpers recognized for their crucial roles in helping people achieve mental health.

I would like to have included the accessibility of counsellors for persons struggling with psycho-social difficulties. When I struggled with clinical depression, a counsellor helped me get my life back together. Effective programs should include a focus on psychological well being and enhancing access to psychotherapy delivered by trained psychologists.

Online Participant British Columbia Online Participant Alberta

### Goal 6: Actions are Based on Appropriate Evidence, Outcomes Are Measured and Research is Advanced

The following key themes emerged from participants' exploration of Goal 6:

What matters can't always be counted and what can be counted doesn't always matter.

Regional Dialogue Participant (with credit to Albert Einstein) Edmonton, Alberta

- 1. The case for greater investments in research must be made even more strongly albeit with some caveats.
- The need for and importance of research that incorporates knowledge derived from lived experience, qualitative methods, and traditional learning and wisdom must be further emphasized.
- This goal should be broadened to include a discussion on the need for knowledge transfer and exchange (KTE), success and performance indicators and program evaluation.

## 6.1 The case for greater investments in research must be made even more strongly – albeit with some caveats

Participants in the Regional Dialogues generally expressed strong support for the important role played by research – including scientific and medical research – in the advancement of effective policies, programs and services.

However, as noted previously (see Chapter 3, Section 3.1), relative to the other seven goals, Goal 6 received the lowest (though still high) support and saw the greatest decline in support (based on pre and post test results).

Because of the biological evidence of some mental illnesses, pharmacological research is important and should continue. Research re: alternate treatments, programs, services and supports should also be funded.

> Online Participant Ontario

Online survey respondents also expressed their support of the importance of research, insofar as over 80% of both public and stakeholders respondents strongly agreed with the statement: *"Funding for mental health and mental illness research should be increased so that it reflects the economic and social costs of mental health problems and illnesses to society"* (see Chart 4.16 – a, below). They also strongly agreed that all levels of government to work together to develop common measures of success for their mental health policies and programs (see Chart 4.16 – b).

On the other hand, their views on scientific and medical research were more ambiguous than those heard in the Regional Dialogues: only 24% of stakeholders and 38% of public respondents expressed high agreement with the statement *"It is important to take the extra time to prove – to a high standard of scientific evidence – that a program works before it is funded"* (see Chart 4.16 – c). At the same time, less than half of online respondents (43% of public respondents and 46% of stakeholder respondents) expressed high agreement with the idea that *"there is too much emphasis on medical and drug research"* (see Chart 4.16 – d).

The bias in service delivery derives from the bias in research with a biological focus.

Regional Dialogue Participant Toronto, Ontario

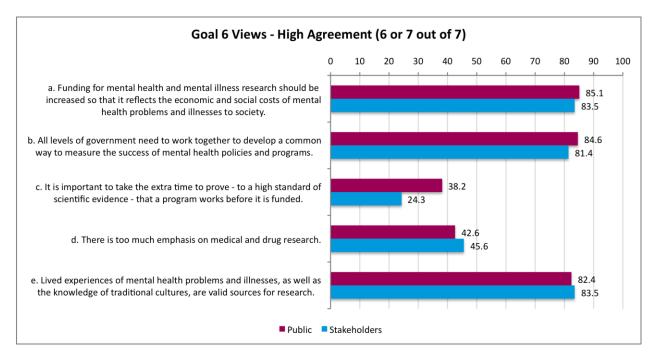
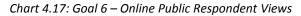
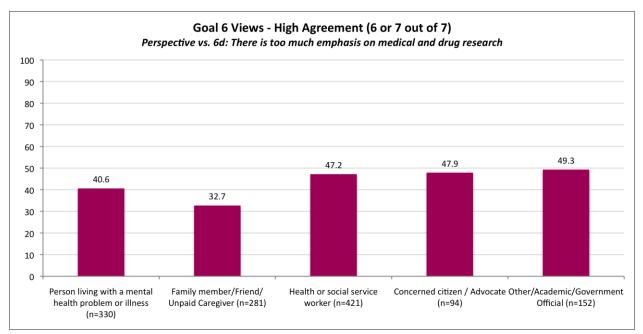


Chart 4.16: Goal 6 – Online Public and Stakeholder Workbook Responses

It is also interesting to note that Family members/friends/unpaid caregivers (33%) and persons living with a mental health problem or illness (41%) were in lesser agreement that there is *"too much emphasis on medical and drug research"* than were the other respondent groups (47% to 49%) (see Chart 4.17, below).





Participants also highlighted the underfunding of research, which was considered to be a symptom of the larger problem of underfunding of mental health needs more generally.

[We need] a call to action – when you look at the people who are dying from MH illness, we can call it a pandemic or epidemic – we need to treat it on par with SARS and other disasters...we need to advocate for research dollars and raise the alarm bells.

Regional Dialogue Participant Edmonton, Alberta

Some participants also expressed concern about potential unintended consequences of elevating research as a high priority. In a context of scarce resources, they worried, this could negatively affect access to necessary services (e.g., by delaying the provision of services, displacing funding for service delivery).

Funding research should be secondary to funding services.

Online Participant Ontario

#### 6.2 The need for – and importance of – research that incorporates knowledge derived from lived experience, qualitative methods, and traditional learning and wisdom must be further emphasized

Participants positioned scientific research as one form of research, within the broader scope of necessary research. They did not dismiss the value and contributions of this kind of research but argued that evidence-based research and policy-making are not as straightforward as they appear – what counts as evidence and who determines this are complex, subjective questions that carry their own set of assumptions and value judgments.

To more accurately reflect this, they suggested the Framework discussion on "evidence-based research" should be more carefully nuanced. Alternate language suggestions included the following descriptors: evidenceinfluenced or informed, evidence and values-based, appropriate evidence that takes into account contextual factors. It is important to recognize that qualitative research and paradigms other than controlled clinical trials are valid forms of research.

> Online Participant Ontario



Elevate lived experience as knowledge – this evidence does not get into the general discourse – unless evidence is in a peer-reviewed journal, Health Service Providers either don't get it or don't believe it.

> Regional Dialogue Participant Halifax, Nova Scotia

Participants also called for this goal to place greater emphasis on the need for participatory and qualitative research methods that value diverse kinds of knowledge – traditional; Aboriginal; experiential; community-based, clinical and scientific – and which are guided by sound ethical and accountability frameworks.

Online respondents concurred with this perspective: over 80% of public and stakeholder participants gave high support to the position that lived experience, and knowledge of traditional cultures are valid sources for research (see Chart 4.16 - e).

# 6.3 This goal should be broadened to include a discussion on the need for knowledge transfer and exchange (KTE), success and performance indicators and program evaluation

Participants stressed the importance of facilitating both the transfer and exchange of knowledge – including *existing* knowledge, which many saw as inadequately tapped – to improve policies, practices and services. Participants also felt that more must be done to reduce the time lag for moving from research to practice, noting that it is imperative that the value of "perfect evidence" be weighed against the magnitude and urgency of the needs of those living with mental health problems or illnesses, their families and society in general.

Related to this, participants also stressed that a practical evaluation focus, with pertinent outcome and program effectiveness measures, is a key dimension of the research that is required. While recognizing that the articulation of performance indicators and measures is perhaps more complicated and challenging for mental health services than for other spheres of health care, participants reiterated the importance of establishing mechanisms that would enable the monitoring of progress and the achievement of objectives – whether at the program/service level or at the system level.

Il faut élargir le concept de banque de données et developer une variété d'indicateurs pour évaluer le système de santé.

> Regional Dialogue Participant Montreal, Quebec

It is a challenge to identify a uniformed and agreed upon measure of success or outcome. This would take some time, work, and cost but in the long term I think that the community and families will benefit from high quality services that work.

> Online Participant British Columbia

Participants also noted the importance of striving to make such performance indicators diverse (measuring different outcomes in different ways) and comparable across jurisdictions (to support the notion of a "national" mental health system). For example, over 80% of online public and stakeholder respondents were strongly in agreement with the need for "all levels of government to work together to develop common measures of success for their mental health policies and programs". (See Chart 4.16 – b).

Funders require metrics – much of this has to do with workload measurement...has nothing to do with what the person needs...we need to balance numbers with true outcome assessments.

Regional Dialogue Participant Halifax, Nova Scotia

Finally, participants noted the importance of putting in place the adequate technology infrastructure and systems (e.g., shared databases) in making data available and accessible to decision-makers.

### Goal 7: Discrimination against People Living with Mental Health Problems and Illnesses is Eliminated and Stigma is Not Tolerated

#### What we heard...

#### Providing venues for sharing of personal experience

My perspective: Person living with a mental health problem/illness

Those of us who have suffered from schizophrenia or psychosis require opportunities to retell our experiences. This can be therapeutic and is sometimes educational and inspiring for others. We have often survived not only the illness but sub-standard treatment in sub-standard facilities where we have been housed because more appropriate services were unavailable.

We need to be involved in the education of mental health workers and related professionals. We need to be invited to speak in our places of work and worship. No strategy will work unless this happens. The reduction of stigma will depend upon the freedom of all to be a part of the public discussion, a discussion which cannot be restricted only to those few who have obtained particular academic credentials.



#### What we heard...

#### A student's experience with discrimination

My perspective: Person living with a mental health problem or illness

I'd like to share my experiences as a university student living with mental illness.

Last year, I was hospitalized for 13 weeks for anorexia, anxiety, and depression. While on the waiting list for a hospital bed, I lived in a student residence managed by my university.

My roommates, who were concerned about my wellbeing, approached the residence manager to discuss my condition, with the goal of learning how to help me out and make our living situation better for all four of us. The residence system, however, took the matter too far into their own hands.

Several weeks after the initial meeting, I was called to a supposedly private meeting with the residence manager, to find the manager of the entire residence system present as well. "Our residences cannot accommodate people like you," they told me, and they informed me that if I showed any more symptoms of my disorders that I would be "removed from the residence system."

It is impossible to immediately recover from a mental illness, or to recover solely based on the orders of another individual. I did my best to hide my illness from my roommates (who had no idea that I faced being kicked out of residence). I was terrified that they'd tattle and that I'd then be homeless. But hiding only made my problems worse. It ended in disaster, with an emergency hospitalization that could have cost me my life, and definitely terrified my roommates, family, and other friends. While I was in the emergency room, my mother (who was unaware that I'd been hospitalized), was awakened with a rude phone call to inform her that I was to be removed from the student residence system.

This institution lied to me, threatened me, and then punished me, all for an illness that I did not choose to have. The residence system provides students with physical illnesses or disabilities, on the other hand, with the best possible accommodations and assistance. I would like people living with mental illness to receive the same consideration as those who are healthy or those with physical diseases or disabilities. The following themes emerged from participants' feedback on Goal 7:

Education is key. People fear what they don't know. Knowledge of what mental health and illness is and skills or supports to help people deal with family, friends or co-workers who are experiencing mental illness will help to reduce stigma. Mental Health First Aid has been a great tool for us to use in our health region.

> Online Participant Alberta

- Fighting stigma and discrimination is critical to improving the lives of persons living mental health problems and illnesses (and their families), and should be a core element of the Framework.
- This goal must more explicitly recognize that stigma and discrimination are embedded in parts of the mental health and health systems – a fact which has had very negative consequences for people living with mental health problems and illnesses.
- 3. This goal's correct emphasis on the mobilization of broad, societal-level momentum must be accompanied by the use of more positive language to normalize mental health problems and illnesses and effectively address stigma and discrimination.
- 4. Fighting stigma and discrimination will also require the active use of legislative, regulatory and policy levers, along with clear indicators of success.

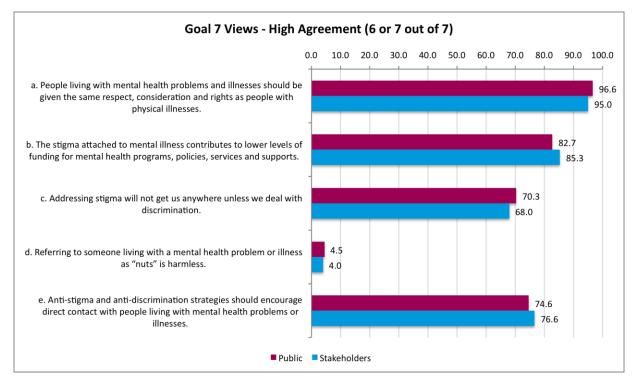
# 7.1 Fighting stigma and discrimination is critical to improving the lives of persons living mental health problems and illnesses and their families, and should be a core element of the Framework

Participants very explicitly and vocally agreed that fighting stigma and discrimination should be a core element of the Framework. Doing this, they noted, will be a key condition of change and critical to improving the lives of persons living with a mental health problem or illness and their families.

There was also a high level of congruence across online and in person reactions. For example, there was quasi-unanimous agreement among online respondents that people living with mental health problems and illnesses should be given "the same respect, consideration and rights as people with physical illnesses" (see Chart 4.18 – a, below) – although in their comments, many disapproved of this comparison, suggesting that it fostered unnecessary "us and them competition" between the worlds of physical and mental disabilities. Ultimately, they added, persons living with mental health problems or illnesses should have the same rights as *all* Canadians. Likewise almost 100% of online respondents disagreed that such insensitive behaviours as calling someone "nuts" are harmless (see Chart 4.18 – d).

Comparatively, however, online respondents were less convincingly in agreement with the notion that you cannot address stigma without addressing discrimination (see Chart 4.18 - c).

Finally, over 80% of online public and stakeholder respondents agreed with the statement "the stigma attached to mental illness contributes to lower levels of funding for mental health programs, policies, services and supports" (see Chart 4.18 - b) – a situation they believed direly needs to be addressed.





It should be noted, as well, that participants embraced a large view of "stigma and discrimination", highlighting that the goal should:

- emphasize the need for major public attitudinal change;
- recognize the reality and compounded impact of racism and related form of discrimination on persons living with a mental health problem or illness; and
- give a more fulsome explanation as to the origins of stigma in relation to mental health problems and illnesses.



#### 7.2 This goal must more explicitly recognize that stigma and discrimination are embedded in parts of the mental health and health systems – a fact which has had very negative consequences for people living with mental health problems and illnesses

It was noted repeatedly that mental health service professionals and health service providers themselves often exhibit stigmatizing attitudes and discriminatory behaviours towards people living with mental health problems and illnesses. Moreover, participants noted, these professionals often do not realize the detrimental effects this has on their clients.

Participants indicated that addressing stigma among these professionals would require investments in training and education – at a minimum. Beyond this, they stated, accountability measures are needed to help ensure that mental health professionals, and health professionals more generally, take responsibility and be held to account for stigmatizing attitudes and discriminatory behaviours.

Notwithstanding the fact that mental health workers need to take responsibility for their own negative attitudes, participants also noted that mental health workers are themselves often stigmatized within the health care system.

Mental Illness...not only affects people with mental illness, but also the professionals that are working to help them. Even Psychiatric Nurses are not looked at as "real nurses" and even as a new grad in psychiatric nursing, I sometimes leave out the "psychiatric" part of my degree, to save my client embarrassment, or because people do not want to be singled out as having a mental illness.

> Regional Dialogue Participant Winnipeg, Manitoba

#### 7.3 This goal's correct emphasis on the mobilization of broad, societal-level momentum must be accompanied by the use of more positive language to normalize mental health problems and illnesses and effectively address stigma and discrimination.

Online and Regional Dialogue participants also consistently believed that an anti-stigma and antidiscrimination strategy must have at its core sustained public and workplace education and awareness initiatives (this was a particularly frequent theme arising from the comments offered by online public respondents).

Many felt that harbouring stigmatizing attitudes is in large measure a result of ignorance and fear, which can only be addressed through active education measures (going well beyond posters and television spots) and personal connections with people with the lived experience.

This point was echoed by online public and stakeholder respondents, roughly 75% of which expressed high agreement with strategies that encourage "direct contact with people living with mental health problems or illnesses" (see Chart 4.18 - e).

Normalize mental illness as an anti-stigma technique – the more people talk about it, the more people realize that it can affect anyone, the better. 40% of the population is affected... Mental illness is really normal! We need to convince ourselves of that.

Regional Dialogue Participant St. John's, Newfoundland and Labrador

As might be expected, persons living with a mental health problem or illness expressed slightly higher levels of agreement with this statement (77%) – followed by family/friend/unpaid caregivers (76%) and health or social service workers (75%) – than did other/academic/government official and concerned citizens (69%) (see Chart 4.19, below).

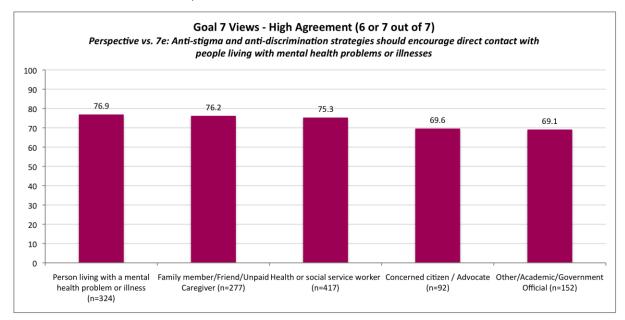


Chart 4.19: Goal 7 – Online Public Respondent Views

Participants noted that the goal should do more to highlight the importance of promoting mental health, and mental illness awareness and sensitivity within the workplace, given that a large proportion of Canadians spend a majority of their waking hours at work. They also noted the important role that employment (in a positive and nurturing environment) can play in one's journey towards recovery.

Stressful work environments are responsible for problems of anxiety, depression and other stress related difficulties in individuals who have previously coped well. Healthy workplace programs will be good prevention methods if companies are given sufficient education to recognize their worth.

Online Participant Ontario

Some also noted that the media can and has played a negative role in creating or perpetuating negative and ill-informed public views, and that more needs to be done to both increase media representatives' understanding of the issues and to hold them to account for incorrect or disparaging coverage.

On doit aussi inclure le rôle des medias – qui font souvent de la déformation plutôt que de l'information.

> Regional Dialogue Participant Montreal, Quebec

[T]he media is often a major culprit in spreading misinformation about mental illness. Part of the effort to fight stigma should include advocates publishing counterarguments to these discriminatory and ill-informed media pieces.

> Online Participant Manitoba

Finally, participants advocated that the framing of this goal be revised to be more positive by using more affirmative and active language, for example, by replacing the term "stigma will not be tolerated" with "stigma will not be accepted." In addition, the goal statement and description should convey the idea that mental health problems and illness are a part of the human condition – and as such invite the full range of expression, including humour and honesty. Reworking the goal in this way would help model the types of attitudes the Commission seeks to promote.

We would like a more positive focus on things – all too often when people hear "mental illness," they go to a gloomy place. We can talk about this normally, with humour, honesty – we need to normalize.

Regional Dialogue Participant Yellowknife, North West Territories



## 7.4 Fighting stigma and discrimination will also require the active use of legislative, regulatory and policy levers

[The document] underplays the potential of the law to confront the impacts of discrimination e.g. Charter of Rights and Freedoms, International Conventions)... It underplays the need for a legal framework to battle discrimination and stigma – section needs to be toughened up.

> Regional Dialogue Participant Edmonton, Alberta

Participants expressed strong views that Goal 7 should more explicitly articulate the types of legislative, regulatory and policy changes that could help combat discrimination.

In the same vein, others advised greater attention to the human rights approaches to fighting stigma and discrimination. As previously noted, this view was well supported by online public and stakeholder participants, almost 100% of which believed that people living with mental health problems and illnesses should be given the same respect, consideration and rights as people with physical illnesses (see Chart 4.18 – a).

Some, however, wrestled with what it means to "not tolerate stigma." They advocated giving greater prominence to discrimination because they felt it was more actionable than stigma, and as such, would be more effective in moving the agenda forward. On the other hand, there were many others who felt quite differently, seeing merit in keeping the goal focused on both stigma and discrimination. This divergence in views was somewhat reflected in the fact that online respondents were less convincingly in agreement with the notion that you cannot address stigma without addressing discrimination (see Chart 4.18 - c) than they were with other statements on this topic.

Stigma is not tolerated – tolerated may not be the best word. Manifestation of stigma is discrimination and that is what we need to address.

> Regional Dialogue Participant Edmonton, Alberta

I think that discrimination springs from the beliefs and attitudes (stigma) therefore they go hand in hand for needed reform.

> Online Participant British Columbia



### Goal 8: A Broadly-Based Social Movement Keeps Mental Health Issues Out of the Shadows – Forever

#### What we heard...

#### Martin Tarback – the first person suffering with schizophrenia and homelessness to have a walk in his honour

My perspective: Family member of a person living with a mental health problem/illness

*My brother Martin died on March 17th, 2009 from throat cancer. He suffered from schizophrenia and homelessness.* 

On March 28th, a memorial service was held for him at St. John's Community Kitchen, in Kitchener, Ontario, and a walk in his honor followed where police officers closed the main street while those on the walk posted his pictures in all the spots he used to frequent leaving red roses behind. The walk was attended by the Mayor, members of the police and justice department, nurses, mental health professionals, and countless members of the community. I don't think that a homeless man with schizophrenia has ever, in history, received such attention and support. Just Google "Martin Tarback". There are numerous newspaper articles documenting what happened and countless examples of how my brother inspired a community of people to change the way they approached someone with his challenges.

The TD Bank changed their policies in dealing with a homeless man with schizophrenia who needed to do banking but wasn't able to deal with some of the social pressures of accomplishing that. The emergency department at Grand River Hospital changed their policies in dealing with a homeless man with schizophrenia who needed medical care but wasn't able to deal with the social pressures of waiting in an emergency room for hours to receive it. The police department invited my brother to participate in police sensitivity training and the DVD is still being shown to new officers. Nurses at Freeport Hospital, the palliative facility where my brother fought his cancer, have been forever changed by his stay there (the first person with a severe mental illness to stay at a hospice in Kitchener/Waterloo).

The alleyway behind an art gallery was like home to my brother - the owner allowed him free access to the space and even to the washroom in the gallery when needed. Because he lived on the streets, and because of his appearance, my brother was a high profile individual. He never asked anyone for anything - people reached out to him because they wanted to. Everyone probably hoped that one day he would change and accept treatment, get off the streets, and "recover". My brother never changed. What changed was everyone around him - how they viewed him - how they reached out to him. I used to always ask myself why did this happen? Now I know my brother had a purpose in life. It was to change the way the Kitchener/Waterloo region responds to people suffering from mental health issues forever.



Participants' comment on Goal 8 illuminated the following themes:

You cannot legislate a "broadly-based social movement". People will either wish to support a social movement, or they will not. By definition, it is not a broadlybased social movement if it is a government organization.

> Online Participant British Columbia

- A successful social movement could help foster change, but the nature of the social movement suggested in the Framework is unclear.
- A number of key success factors are required to foster and sustain a successful social movement and should be clearly outlined in this goal.
- Notwithstanding support for the idea and importance of a social movement, many questioned its inclusion as a Framework "goal."

## 8.1 A successful social movement could help foster change, but the nature of the social movement suggested in the Framework is unclear

In general terms, participants agreed that successful social movement can help foster change, frequently citing as an example the progress driven by well-organized, well-resourced movements such as the AIDS movement.

However, participants also clearly had varied understandings and perceptions of what a social movement is, what it should strive to achieve, and how it might foster change.

Social movements more than watching famous people come forward – it's also about everybody coming forward, feeling free to say I'm going to my psychiatrist, I have depression...it's also about personal transformation.

Regional Dialogue Participant Yellowknife, North West Territories

I support where I think this goal is going, but it is too general to be meaningful. I am not really clear as to what a "broad based social movement" is.

Online Participant Ontario

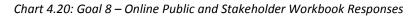


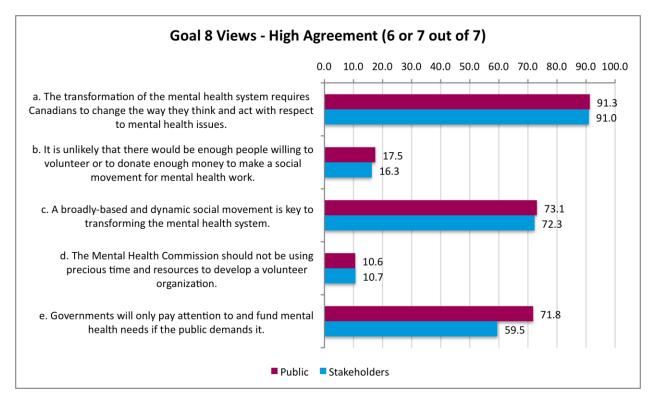
Governments move slowly – we can't count on them to drive change and many of the necessary changes are not legislative. A social movement will hold the government's feet to the fire.

> Regional Dialogue Participant Government of Canada Session, Ottawa

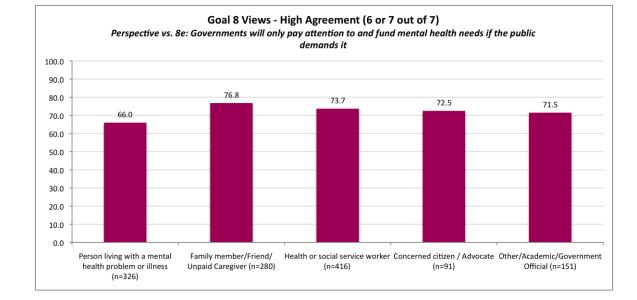
Perhaps reflecting this confusion, online respondents' support for the notion of a social movement also appeared somewhat mitigated relative to, for example, their overwhelming agreement (91%) that *"the transformation of the mental health system requires Canadians to change the way they think and act with respect to mental health issues"* (see Chart 4.20 – a, below).

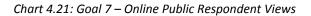
Only slightly over 70% of online respondents agreed that "a broadlybased and dynamic social movement is key to transforming the mental health system" (see Chart 4.20 – c). Similarly, only 60% of stakeholders (and 72% of public respondents) agreed with the notion that "governments will only pay attention to and fund mental health needs if the public demands it" (see Chart 4.20 – e).





Interestingly, family members/friends/unpaid caregivers were the most numerous to agree with the efficacy of public pressures on government (77%), while persons living with a mental health problem or illness were the least (66%) (see Chart 4.21, below).





## 8.2 A number of key success factors are required to foster and sustain a successful social movement and should be clearly outlined in this goal

Participants' direction in regards to how to build and sustain an effective social movement points to five key success factors. A social movement should be:

A social movement needs to be sustained, structured, supported and funded.

Regional Dialogue Participant Edmonton, Alberta

People living with mental health issues are needed as key players in this endeavour.

> Online Participant British Columbia

- Funded in a sustainable manner;
- Bottom-up, led by people with lived experience, and allied with community-based organizations;
- Supported by strong champions/advocates;
- Underpinned by solid public outreach and education strategies (many participants linked this back to the type of public education called for in the context of Goal 7);
- Independent from both the government and the Commission, although when asked, online participants clearly saw a role for the Commission in developing a volunteer organization – only 11% of online respondents disagreed with the notion that the Commission use precious time and resources to this end (see Chart 4.20 – d).

In addition, participants were also concerned that the Framework goal puts too much burden and too high expectations on volunteers, with inadequate recognition of the resources and supports required to sustain effective action. Notwithstanding, approximately 85% of online respondents appeared to believe that there would likely be enough people to volunteer or donate money to make such a movement work (see Chart 4.20 - b).

The use of volunteers at a board level is OK but to think volunteers will help us solve this problem when professionals have failed is really asking too much.

Online Participant British Columbia

There is a need for key champions so the full responsibility for the social movement is not on the shoulders of consumers/family members.

Regional Dialogue Participant Winnipeg, Manitoba

Both the regional sessions and online responses also revealed participants' high regard for the work of existing service and advocacy organizations, consumer groups and volunteers who have done so much to advance mental health literacy and improve life for people living with mental health illnesses and problems. Participants want to ensure that the Framework in general, and this goal in particular, recognize their work and include them as key assets in the construction of a larger social movement. Moreover, participants gave clear direction to the Commission that it should not be "reinventing the wheel", but rather, helping pull together all the different players so as to generate real synergies, where the power of the whole is greater than the sum of its parts.

The social movement is already there. What we need is the support, funding etc., to glue it all together and be inclusive of different populations and groups.

Regional Dialogue Participant Halifax, Nova Scotia

I think the volunteer organizations for mental health are important and can better define the needs in the community with which they reside. They do need funding, but they also need resources and direction. We should all be promoting the same messages.

> Online Participant Alberta

### 8.3 Notwithstanding support for the idea and importance of a social movement, many questioned its inclusion as a Framework "goal"

Regional participants strongly advised the Commission to rethink Goal 8's positioning and inclusion as a Framework goal, but were divided on how this should be done:

- some felt that the essence of Goal 8 would be better captured in the form of a vision statement;
- others suggested that this concept should be positioned in the preamble of the document;
- others yet thought that Goal 8's message should be weaved into the other seven goals; and
- some believed that what Goal 8 proposed was less of a goal and more of a mechanism by which the other goals would be realized.

[Goal 8] is the stage from which we move to action – this could be the bridge function.

> Regional Dialogue Participant Vancouver, British Columbia

This is the greater goal that either will happen because of the achievement of the other goals or will make possible the achievement of the other goals.

> Regional Dialogue Participant Whitehorse, Yukon

This is not a goal like the other 7 – it is a mechanism, a way to reach goals, rather than a means to an end.

> Regional Dialogue Participant Thunder Bay, Ontario