



Canadian
Collaborative
Mental Health
Initiative

Initiative
canadienne de
collaboration en
santé mentale

**National Consultations for the
Collaborative Mental Health Care Charter**

Consumers, Families and Caregivers



July 2005

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Acknowledgements

The authors would like to especially thank each consumer, family member and caregiver for their time, expertise and valuable insights in the consultations. The authors would also like to thank the local community coordinators for organizing the consultations and ensuring broad representation, and the CCMHI Steering Committee organizations who were instrumental in supporting this process: Canadian Alliance on Mental Illness and Mental Health (Mood Disorders Society of Canada, Schizophrenia Society of Canada) and Canadian Mental Health Association.

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Suggested Citation: Bourget B., Chenier R. National consultations for the collaborative mental health care charter: consumers, families and caregivers. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario, Canada; July 2005. Available at: www.ccmhi.ca

Ce rapport est disponible en français.

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This document was commissioned by the CCMHI Secretariat. The opinions expressed herein do not necessarily reflect the official views of the Steering Committee member organizations or of Health Canada.

Funding for the CCMHI was provided by Health Canada's Primary Health Care Transition Fund.

**National Consultations for the
Collaborative Mental Health Care Charter:**

Consumers, Families and Caregivers

A report for the
Canadian Collaborative Mental Health Initiative

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July 2005



O u r G o a l

The Canadian Collaborative Mental Health Initiative (CCMHI) aims to improve the mental health and well-being of Canadians by enhancing the relationships and improving collaboration among health care providers, consumers, families and caregivers; and improving consumer access to prevention, health promotion, treatment/intervention, and rehabilitation services in a primary health care setting.



FOREWORD

National Consultation for the Collaborative Mental Health Care Charter: Consumers, Families and Caregivers

When the Steering Committee of the Canadian Collaborative Mental Health Initiative (CCMHI) set out to design a process for the development of a charter, it was quickly determined that the governing bodies of the organizations represented on the CCMHI Steering Committee would need to be assured that their members have had a hand in developing the charter and that the charter reflects the wisdom, experience and aspirations of people at the front lines.

In particular, it was further determined that the governing boards of the national associations who make up the Steering Committee, the potential signatories, would need to hear from the recipients of mental health services – consumers, their families and other caregivers. This is especially important given that it was clear that the charter would contain principles supporting consumers and their caregivers as partners on collaborative mental health care teams.

Accordingly, we determined that the starting point for consultation on the draft charter principles would be with consumers, families and caregivers across the country. Working with an expert facilitator who has personal experience with mental illness, CCMHI reached out to member organizations in seven cities across the country for assistance in locating consumers, family members and caregivers in their communities. Local community coordinators organized consultation meetings in libraries, community centres or local offices of one of our organizations. This consultation process, involving an incredible variety of consumers, family members and caregivers in Halifax, Montreal, Sudbury, Winnipeg, Saskatoon, Whitehorse, and Vancouver, has delivered rich advice to the Steering Committee and has served as a solid foundation for the remainder of the charter development process. With revisions to the Charter Principles based on this report, we went back across the country to ask mixed groups of providers, consumers and caregivers for advice on what actions need to be taken to ensure the principles of

collaborative mental health care prevail. The charter will be completed in the fall of 2005.

The Steering Committee was struck by the hope expressed by consumers, family members and caregivers that as a result of this work, the mental health care system would work better for them, in ways that make sense to them. As leaders of NGOs that serve consumer and family members, we were asked if this report rings true. We believe that this report is a true reflection of what we heard from consumers, families and caregivers. It voices their experiences and views of what solutions might work. We also believe that this document will be useful for anyone considering how to improve the delivery of mental health care services in the context of primary health care.



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INTRODUCTION

Federal, provincial, and territorial jurisdictions across Canada have agreed on the importance of improving the organization and delivery of primary health care – making it more accessible, comprehensive, interdisciplinary, coordinated and oriented to health promotion. This is particularly critical for mental health services, which are poorly coordinated, stigmatized and difficult to access.

The goal of the Canadian Collaborative Mental Health Initiative (CCMHI) is to improve the mental health and well being of Canadians by enhancing the relationship and improving collaboration among health care providers, consumers, families and caregivers.

CCMHI is a consortium of 12 national associations. These 12 organizations represent community services, consumers, families, caregivers and self-help groups, dietitians, family physicians, nurses, occupational therapists, pharmacists, psychiatrists, psychologists and social workers from across Canada. They have come together because each has a stake in the provision of mental health services. They all recognize the critical importance of accessible, high quality mental health services, and believe that improved collaboration among care providers, consumers, families and caregivers is the key to achieving that quality.

These associations have agreed to jointly develop a Charter for Collaborative Mental Health Care. The final Charter will articulate a set of value statements called **Principles** that characterize good collaborative mental health care in the primary health care context, combined with **Commitments** that state actions for working together to enact these Principles now and into the future.

Key Findings

The 145 participants:

- ✓ thought that all of the Charter Principles should be articulated with simpler, more assertive and less tentative language;
- ✓ made suggestions for modifications to the Principles;
- ✓ supported the Principles, some qualified their acceptance of particular Principles by saying that they would support them if the proposed changes were made.

CCMHI contracted with *Chenier Consulting Canada* to facilitate consultations and solicit feedback from consumers, family members and caregivers across the country on the first part of the Charter, the Principles. The goal of the consultations was to ensure that these Principles truly reflected the experiences and aspirations of people that have both knowledge of the current mental health services and a sense of how services can be strengthened.

Participants were asked to comment on the following proposed Principles:

Figure 1 – Draft Charter Principles, April 2005

- 1. We believe that all Canadians have a right to appropriate and timely mental health services.*
- 2. We affirm that the needs of the individual should direct the provision of mental health services.*
- 3. We support improved access to collaborative mental health services in primary health care settings.*
- 4. We believe that mental health services need to be flexibly configured to provide access to appropriate providers to meet the varying needs of each individual receiving care.*
- 5. We recognize individuals requiring mental health services and their families are partners in decision-making about their health care.*
- 6. We believe that individuals should expect to have services that respect their cultural beliefs and preferences.*
- 7. We believe that effective collaboration requires:
 - a) Mutual respect and support;*
 - b) Willingness to learn from each other;*
 - c) Knowledge of the skills and competencies of fellow members of the interdisciplinary team;*
 - d) Effective communication;*
 - e) Clearly articulated and mutually agreed upon treatment goals;*
 - f) Shared decision-making;*
 - g) Clear definitions of roles and responsibilities; and*
 - h) Mutual accountability.**
- 8. We acknowledge the value of articulating and communicating the range of service options for persons requiring mental health services.*
- 9. We will speak with one voice to government about the need for policies, legislation and funding mechanisms that facilitate access to collaborative mental health care.*

METHODOLOGY

As part of the development of a Charter for Collaborative Mental Health Care, the CCMHI held a series of 14 consultations with consumers, families and caregivers across Canada from April 11-23, 2005. The participants actively engaged in discussions about the quality of existing mental health services and the nine drafted Charter Principles. (Figure 1)

Group discussions were held in Halifax, Montreal, Sudbury, Winnipeg, Saskatoon, Whitehorse and Vancouver. Each group was designed to have ten to 12 participants with various background experiences (as a consumer, family member or caregiver). In total, 145 people participated in the discussions.

The consultations were intentionally designed to get a broad cross-section of participants (including factors such as: gender, age, socioeconomic factors, ethnicity, Aboriginal, urban, rural). Consultations with specific groups were held in different cities: Seniors (Halifax and Saskatoon); multicultural groups (Montreal and Vancouver) (including one group held in French); youths (Sudbury and Vancouver); Francophones (Sudbury and Montreal); and, First Nations, Aboriginal or Métis groups (Sudbury and Winnipeg) (See Appendix I: Timetable and Participants).

Invitations were sent through local “Community Coordinators”. The Community Coordinators were identified by Chenier Consulting Canada and represented the local chapter of the Mood Disorders Society of Canada, Schizophrenia Society of Canada, Canadian Mental Health Association, or an independent self-help organization.



Participants were asked to check a box on the sign-in sheet indicating if they were a consumer, caregiver, family member or other (service provider). Several people indicated that they were both a consumer and caregiver.

Meetings were held in accessible settings such as the local library, the community centre, the YMCA, or the offices of one of the above associations.

Each participant was paid an hourly honorarium to attend the consultations, as well as incidental costs such as mileage and parking.

The discussions were facilitated by Richard Chenier of Chenier Consulting Canada. All discussion was taped and notes were manually taken (without identifying information) by his associate, Beverley Bourget. One or two CCMHI Secretariat staff attended each session to provide a background context and to answer any questions about the CCMHI. Several sessions were also attended by one of the CCMHI Steering Committee members, Ms. Joan Montgomery, CEO of the Schizophrenia Society of Canada and member of the Canadian Alliance on Mental Illness and Mental Health.

A short video describing collaborative mental health care in primary health care settings was shown at the beginning of each consultation. All 14 groups then reviewed the CCMHI Charter Principles (in a two-hour session).

Seven of the groups also provided input related to the development of a Consumers, Families, and Caregivers *Toolkit* (the third-hour in a three hour session). This Toolkit is being developed by CCMHI to provide constructive methods and practical approaches for supporting consumers, families and caregivers to: 1) actively participate on the collaborative mental health care team, and; 2) fully participate at the governance level. One of the groups also provided input related to Clinical Toolkits for Aboriginal and Remote/Rural Populations.

FINDINGS

Participants

One hundred and forty-five people participated in the consultations across the country. Sixty-one people identified themselves as consumers of services, 45 people identified themselves as caregivers or family members, and one self-identified as a service provider. Seventeen did not check a box on the sign-in sheet. However, when individuals were introducing themselves verbally prior to the discussion, several indicated that they were also service providers. Some consumers said that they were also caregivers.

Sixty-five of the participants were male and 80 were female. At least 11 were Francophone and 20 people self-identified as First Nations, Aboriginal or Métis. Twenty-two participants were youth or young adults under 30 years of age and at least 20 participants were over 50 years of age.

Results

Summary of Discussion: Charter Principles

Every participant was provided with a copy of the Charter Principles. The facilitator reviewed each statement with the group and encouraged open discussion and feedback.

The participants responded to each Charter Principle individually before moving on to the next. (See Appendix II: Participant Feedback to Charter Principles, for a summary of the discussion of each Principle.)

Overall, participants thought that all of the Charter statements should be articulated with simpler, more assertive and less tentative language. Many participants made suggestions for modifications to the content of the statements. Some qualified their acceptance of particular

statements by saying that they would support them if the proposed changes were made.

Consumers, families and caregivers appeared to enjoy the opportunity to share their views about mental health care generally and collaborative mental health care specifically. Some of the participants reported personal knowledge or direct experience with some form of collaborative care; their comments were uniformly positive about the quality of care provided by collaborative mental health care teams. They showed considerable support for the CCMHI initiative and gave unanimous support in principle for the Charter as a whole.

Several key themes arose across the discussions.

Consumers, families and caregivers generally understood collaborative mental health services to be *a network of professional caregivers who work together, communicate and share information, with the consumer at the centre*. Most were supportive of the concept of collaborative care for mental health services in primary health care settings.

Consumers, families and caregivers agreed that collaborative care needs to be timely and appropriate; for most this means *access to the right kind of services when needed and services that meet the needs of the individual consumer*. Timely means early intervention, shorter wait times for accessing psychiatrists and other mental health professionals, and flexibility in hours of service provision, especially with regard to crisis services. Most understood appropriate to mean accurate diagnoses, proper and effective use of medications and adequate follow-up. Accessibility is closely related to affordability; in a number of the discussions people mentioned that they would like to use counselling or other services but cannot afford them.

To be truly appropriate, collaborative mental health care must provide access to a *broad range of services and supports*. This appears to be very important to consumers,

families and caregivers as it was identified as a service need in several discussions. People would like to have more choice about what kind of help they can access and, along with this, enough services available to be able to make a choice. Services must also be available close to home.

Beyond conventional medical services, the services and supports that participants would like to be able to access within a model for collaborative mental health care include:

- ✓ Psychotherapy
- ✓ Social work
- ✓ Addiction services
- ✓ Community-based peer support/consumer advocates
- ✓ Physical exercise (e.g., health clubs)
- ✓ Alternative health care (e.g., acupuncture, massage therapy, naturopathy, yoga, meditation, etc.)
- ✓ Spiritual support
- ✓ Support/assistance with basic needs (e.g., housing, employment, education)
- ✓ Traditional Aboriginal Healers and Elders (for Aboriginal people)

A range of resources implies a *holistic approach to treatment* and many of the participants emphasized the importance of treating the whole person. Consumers do not want to be viewed as a disorder or diagnostic label; they want to be seen as the diverse and individual human beings that they are. Closely related to this, services must be responsive to diverse individual needs and oriented toward improving quality of life. As such, they will provide access to resources to meet physical, social, economic and spiritual needs regardless of the individual's economic status, level of functionality or race. Participants emphasized the linkages between mental health, physical health and broader determinants of health such as socioeconomic status and education. Basic needs such as housing and nutrition are considered critical influences on overall health and well being.

Another important issue is the need to be *treated with dignity, respect and compassion by mental health professionals*. People want to be open with their family physicians about their concerns, needs and preferences, they want to be heard, and they want to feel safe with professionals. Consumers continue to experience considerable stigma and discrimination within the health care system. Several people also commented that the stigma is further compounded by racism.

Across the groups, many people talked about the need to recognize *faith and spirituality as key elements in healing and wellness*. Beliefs and practices related to faith and spirituality must be treated with as much respect as cultural beliefs and practices. At the same time, the issue needs to be handled delicately. While spirituality plays a significant role in health and healing, providing many consumers with hope and sense of meaning, it is also associated with some risks. People made a distinction between healthy spirituality, which promotes mental health, and unhealthy religiosity.

Participants generally agreed that collaborative mental health care should *respect the cultural beliefs and preferences of consumers*. While it is not always possible to provide services appropriate to every cultural tradition, it is important for service providers to respect these traditions. Cultural competency is essential – any model for mental health care must be developed with an understanding of the background and culture of people being provided service and in the context of what is culturally important for maintaining health and wellness.

Each of the groups struggled with how to *balance consumer rights to empowerment and confidentiality with the rights of family members to be informed and engaged partners*. Most supported the concept of consumer empowerment, but many also acknowledged that consumers are not always well enough to make their own decisions. Many thought that family members or designated caregivers should be full partners on collaborative care teams. However, some were

strongly opposed to the idea of automatically including family members. Most of the participants concluded that while family involvement is ideal, it is not always appropriate. Many supported the idea of having a designated caregiver or advocate (e.g., family member, partner, friend, case worker) as support members on the collaborative care team.

The need for *more education and awareness about mental health and mental illness* – for consumers, family members, the general public and mental health professionals – was identified in response to several of the Charter Principles. People thought that more education and awareness would reduce stigma, enhance prevention and early intervention, promote consumer empowerment and improve mental health care.

Some concerns were voiced about *mutual accountability* and how team members could be held accountable to each other, including the consumer. Mechanisms need to be established to ensure accountability. Most people were supportive of the idea of the CCMHI *communicating consistent messages to government and speaking with one voice*, as long as the voice is inclusive of varying perspectives in the mental health and mental illness communities. Participants want assurances that individual and marginalized voices will not be overshadowed and will continue to be heard.

Summary of Discussion: Consumer, Family and Caregiver Toolkit

The CCMHI promotes the active participation of consumers, families and caregivers at all levels of collaborative mental health care including the decision-making process around treatment and setting goals for recovery; and the design, evaluation, and governance of collaborative mental health care initiatives.

A Consumers, Families and Caregivers Toolkit is being developed by a select group of interested consumers, family members and caregivers led by the CCMHI Steering Committee members representing the Canadian Alliance on Mental Illness and Mental Health. This Toolkit will provide constructive methods and practical approaches for actively involving consumers, families and caregivers as participants in collaborative care.

A consistent theme throughout all of the seven group discussions was the need for all information to be provided in clear, easily understandable language. (See Appendix III: Participant Feedback to Consumer, Family and Caregiver Toolkit.)

Participants also indicated that they would benefit from the following services and information:

- ✓ Information about the full range of service and support options
- ✓ Realistic information about the illness, treatment and the process of recovery
- ✓ Information about the roles and responsibilities of all collaborative care team members
- ✓ Education and support for consumer self-advocacy
- ✓ Information about how to find/establish an advocate/support person or network
- ✓ Information about ways to ensure accountability of service providers and monitor service quality
- ✓ Information and support in dealing with family members
- ✓ Material that encourages people to continue on the path of recovery
- ✓ Information about financial support, employment and education
- ✓ Access to stories of recovery

Participants also indicated that to be partners and participate in the governance of collaborative mental health initiatives, they would need:

- ✓ Support and assistance for full inclusion as an equal partner
- ✓ Support to ensure accountability
- ✓ Information about program evaluation
- ✓ Remuneration for participating

SUMMARY

Although it is difficult to capture the emotional context in a report such as this, according to the written evaluation forms and the verbal feedback from participants, the over-riding response expressed across the country was a sense of hope. There was hope in that the CCMHI even existed and that mental health issues were being looked at, hope in the knowledge that this is a federal initiative and that mental health is an important issue at the highest political level, and hope in the potential of collaborative mental health care to respect and meet the needs of the individual consumer, their families and their caregivers.

NEXT STEPS

Based on the excellent advice and feedback from the Consumer, Families and Caregivers consultations, the CCMHI Steering Committee revised the Charter Principles. The revised Principles are clearer, stronger and inclusive of the feedback. They were approved by the CCMHI Steering Committee in May 2005. (*Figure 2*)

CCMHI will take the revised Principles and solicit ideas for actions to implement them at seven Expert Advisory Forums being hosted across the country in June 2005. The Forums are intended to bring people together from various health disciplines working in mental health along with representatives from consumer, family and caregiver associations. The Forums are designed to identify and

discuss ways to strengthen collaborative mental health care in primary care settings.

Finally, the feedback from the consumer, families, and caregiver consultations inspired the CCMHI Steering Committee to strengthen its Vision statement.

Making Mental Health Care Work New Partners, New Places, New Hope

Figure 2 – Revised Charter Principles based on Consultations with Consumers, Families and Caregivers, as adopted by CCMHI Steering Committee, May 2005.

- 1. All Canadians have a right to appropriate and timely health services that will support a healthy mind, body and spirit.*
- 2. The needs of the individual will direct the provision of mental health services.*
- 3. Access to collaborative mental health services in primary health care settings will be improved.*
- 4. Mental health services will be flexible to meet the varying needs of each individual receiving care.*
- 5. Individuals receiving mental health services are respected partners in their health care. Families, caregivers and/or support networks may also be partners if directed by the individual.*
- 6. Individuals expect to have services that respect their cultural and spiritual beliefs and preferences.*
- 7. Effective collaboration requires:
 - a) Mutual respect and support;*
 - b) Willingness to learn from each other;*
 - c) Knowledge of the skills and competencies of fellow members of the interdisciplinary team;*
 - d) Effective communication;*
 - e) Clearly articulated and mutually agreed upon treatment goals;*
 - f) Shared decision-making;*
 - g) Clear definitions of roles and responsibilities; and*
 - i) Mutual accountability.**
- 8. The range of service and support options for persons requiring mental health services will be communicated to the consumers, families and caregivers.*
- 9. We will speak with one voice to government about the need for policies, legislation and funding mechanisms that facilitate access to collaborative mental health care.*

APPENDIX I - CONSULTATION TIMETABLE AND PARTICIPANTS

Location and Date	Time	Type of Group	Participants
Halifax			
April 13	1-4 p.m.	Seniors Consumers + Caregivers	Total: 10 5 men, 5 women (7 consumers, 3 consumers and caregivers)
	7-9 p.m.	Caregivers *All caregivers were family members	Total: 9 3 men, 6 women (5 caregivers, 2 consumers and caregivers, 1 caregiver)
Montreal			
April 14	1-4 p.m.	Multicultural Consumers Caregivers (FRENCH)	Total: 10 4 men, 6 women (1 consumer, 3 family members, 1 consumer and caregiver, 5 did not say)
	7-9 p.m.	Multicultural Consumers Caregivers	Total: 10 2 men, 8 women (5 consumers, 4 caregivers, 1 consumer and caregiver)
Sudbury			
April 15	1-4 p.m.	Francophone/bilingual Aboriginal Consumers Caregivers	Total: 10 3 men, 7 women (5 consumers, 2 caregivers, 3 consumers and caregivers)
	7-9 p.m.	Francophone/bilingual English, Aboriginal Youth (16-21)	Total: 10 3 men, 7 women (3 consumers, 1 family member, 6 consumers and caregivers)
Winnipeg			
April 18	1-4 p.m.	Aboriginal Consumers Caregivers	Total: 13 10 men, 3 women (6 consumers, 3 caregivers, 2 consumers and caregivers, 2 did not say)
	7-9 p.m.	Aboriginal Consumers Caregivers	Total: 8 2 men, 6 women (4 consumers, 2 consumers and caregivers, 2 caregivers)

Saskatoon			
April 19	2-5 p.m.	Seniors	Total: 10 6 men, 4 women (3 consumers, 5 caregivers, 2 family members)
	7-9 p.m.	Young Adults (18-24) Caregivers Consumers	Total: 11 8 men, 3 women (7 consumers, 1 consumer and caregiver, 1 family member, 2 caregivers)
Whitehorse			
April 21	1-4 p.m.	Aboriginal consumers and caregivers	Total: 9 2 men, 7 women (4 family members, 1 service provider, 2 consumers & caregivers, 2 did not say)
	7-9 p.m.	Mix of consumers and caregivers	Total: 13 6 men, 7 women (3 consumers, 9 caregiver, 1 did not say)
Vancouver			
April 22	2-4 p.m.	Multicultural consumers and caregivers	Total: 11 6 men, 5 women (9 consumers, 1 family member, 1 did not say)
April 23	10-1 p.m.	Youth	Total: 11 5 men, 6 women (8 consumers, 3 did not say)

APPENDIX II - PARTICIPANT FEEDBACK: CHARTER PRINCIPLES

Each participant received a written copy of the nine proposed Charter Principles. Each Principle was read out by the facilitator and then discussed in detail, one at a time. Notes from the discussion, some specific comments and any resulting changes to the Principle statements are outlined below.

Principle #1 - All Canadians have a right to appropriate and timely mental health services that support a healthy mind and body.

Participants were asked to define what appropriate and timely meant to them and if they agreed with the statement.

A consistent theme that emerged across all the groups was that it meant *having access to the right kind of services when needed*. For most, this means having services that meet the needs of the individual consumer.

The importance of early intervention (getting help before you go into crisis) was mentioned by almost half of the groups. Closely related to this, ten of the fourteen groups thought that shorter wait times for accessing psychiatrists and other mental health professionals is important.

In the Montreal Francophone group, some commented that they had good access to services, prompting others to wonder if consumers who seek services in English have better access than those who prefer to use French-language services.

Half of the groups suggested that appropriate and timely services means earlier and more accurate assessments and diagnoses, and two groups talked about the need to ensure the proper medication is given. Several people said that they had been misdiagnosed or given the wrong medication and

"It means appropriate for you – it is different for everyone – not everyone fits the same model."

Montreal Consumer,
Anglophone Group

"J'ai du attendre deux ans et pendant ces deux ans là, j'aurais pu me suicider dix fois." [“I had to wait two years, and during those two years I could have committed suicide ten times.”]

Montreal Consumer,
Francophone Group

"Diagnosis is one thing, but there is no plan. They just give you medication. I have had to take responsibility for managing my own health care."

Vancouver Consumer,
Multi-Cultural Group

"In other communities [outside Whitehorse] people might be sent away and when they come back there is no support in their communities. Often the only support they have is the social worker or police – they [providers] have to wear many hats and work beyond their skills and it stretches them to the limits."

Whitehorse Service Provider

"Timely means available 24 hours a day – consumers don't choose when to have their crises. An eight hour delay can mean the difference between a short hospital stay and one that lasts months."

Montreal Consumer,
Anglophone Group

that long wait times to see psychiatrists made it that much harder to get reassessed.

More than half of the participants across the country mentioned the need for adequate follow-up and after-care following diagnosis, and many thought that community-based support is needed. The need for follow-up support is particularly acute in rural and remote areas.

Access to adequate crisis intervention services was mentioned by four of the groups, and in three groups participants thought that these services should be available twenty-four hours a day, seven days a week.

Two groups said that 'appropriate and timely' meant shorter waits at family physician offices. The Winnipeg Aboriginal group noted that many people use walk-in clinics because they do not have a family physician. They would like to see the quality of mental health care at walk-in clinics improved and alternatives to walk-in clinics made available.

Access to a range of resources emerged as a theme in more than half of the groups, and participants suggested that many services and supports (outside the conventional medical system) should be considered appropriate. They would like to have more choice about what kind of help to get and, along with this, enough services to be able to make a choice. This includes access to psychotherapy, social work, nurse-practitioners, occupational therapy, addiction services, community-based peer support, physical exercise (e.g., health clubs), and alternatives such as acupuncture, massage therapy, naturopathy, yoga, meditation and the like. Some stated that the existing system of services is too fragmented and more coordination and integration are needed.

For many Aboriginal people, 'appropriate' means culturally appropriate services, such as traditional healing and Elders. In Whitehorse, participants indicated that they had received funding from the federal government to provide culturally appropriate services, but only for two years. In reference to

this, one woman stated: “We are talking about basic human rights and you shouldn’t have to write a proposal to get these services.” Participants in Whitehorse also spoke about the need for services for persons with addictions and Fetal Alcohol Spectrum Disorders, especially in First Nations and Aboriginal communities.

Accessibility was closely related to affordability – several participants mentioned that they would like to use counselling or other services but cannot afford them.

Having access to a range of resources implies a *holistic approach to treatment*, and more than half of the groups emphasized the importance of treating the whole person. Consumers do not want to be viewed as a disorder or diagnostic label; they want to be seen as the diverse and individual human beings that they are. Most participants see a linkage between physical and mental health. Indeed, in two of the groups, people commented that the physical health of persons with mental illness is often neglected, and there should be closer collaboration between physical and mental health care providers. For example, one consumer developed a thyroid condition related to her use of lithium, but the psychiatrist would not treat her thyroid condition and the endocrinologist would not treat her bi-polar disorder.

Many people liked the emphasis on healthy mind and body, and several suggested adding the word “spirit.” Aboriginal participants spoke about how a holistic approach is inherent to the traditional Aboriginal worldview and to the importance of connectedness to the land in health and healing.

Another key theme for more than half of the groups was *the importance of being treated with dignity, respect and compassion by mental health service providers*, particularly physicians and psychiatrists.

“[Appropriate is] not just a medical/clinical/medication approach. You need to look at the whole person and their life experience and context.”

Winnipeg Consumer,
Aboriginal Group

“Doctors, psychiatrists and other professional team members, when they decide to take on a health care career, they should know that what they say to a person is so important. They can change a person’s life by how they respond to him or her in one moment.”

Winnipeg Consumer,
Aboriginal Group

"Doctors don't listen closely enough to the clients about their symptoms and especially side effects to medications. It was a social worker who thought maybe my medication was wrong."

Vancouver Consumer,
Youth Group

"There is often more stigma in the health care world than outside it."

Halifax Caregiver

"Mental health care should be empowering, non-shaming, give choices in care, provide information about resources available. Professionals should be advocates for consumers...advocacy is a key part of the therapeutic process."

Winnipeg Participant,
Aboriginal Consumer Group

Many said that "doctors" (referring to both family physicians and psychiatrists) do not really listen to consumers, family members or caregivers. Some said that they can access services, but family physicians do not spend enough time with them. People want to be open with their physician about their concerns, needs and preferences, they want to be heard, and they want to feel safe with professionals. Some participants stated that family physicians are not very well informed about mental disorders and that they are often reluctant to treat people with mental illnesses.

Youth in Saskatoon reported being treated "normally" by physicians and nurses for a physical health issue, until they disclosed they had a mental illness, at which point the service providers focused attention on the mental illness. "If you have a mental health problem, they think it [your physical health problem] is all in your head", said one. This suggests that persons with mental illness may be at risk of not receiving appropriate care for physical health problems. Several participants commented further that people have to "act out" or threaten suicide to get help, which compounds the stigma. Others reported being treated very poorly by hospital emergency room staff, paramedics and auxiliary staff, such as security guards.

Several people stated that family physicians do not support the use of alternative practitioners or community-based resources and will not refer consumers or family members to these services and supports. A number of participants suggested that physicians need better training to ensure that the care they provide is appropriate, including education about consumer needs, the importance of empathy and respect, and information about the range of resources for consumers and family members. Other service providers – police, security guards, nurses, paramedics – need education and sensitivity training as well.

In order to be truly appropriate, it is also important that services be available close to home. For example, the two Whitehorse groups spoke of the difficulty accessing services in remote and rural areas, particularly culturally appropriate services. They noted further that lack of transportation is a real barrier to accessibility for low-income consumers.

Proposed Statement Changes

The following modifications or additions were proposed:

“I would change the statement to read: *All Canadians have a right to client-centred services in a timely manner.* That means I am the centre of the services...and have the right to choose.”
(Montreal Consumer, Anglophone Group)

“Add: *the best and well-coordinated mental health services.*”
(Montreal Consumer, Anglophone Group)

“I would adjust the statement to add *“accessible or affordable”*... I need counselling, but I can’t afford to pay for it”. (Sudbury Consumer)

“It should say: *healthy mind, heart, spirit and body...wholeness, not just mind and body.*” (Sudbury Consumer)

“‘Healthy mind and body’ is kind of a cliché. The statement should say something about physical health also...it is not strong enough the way it is”. (Agreed by all participants, Sudbury Consumer/Caregiver Group)

“You should add *spirit*...most of us in the Yukon take a more holistic view...healthy mind, body and spirit and the importance of the land.” (Service Provider, Whitehorse Group)

“Add something about *‘quality of life’*”. (Halifax Caregiver)

“The statement has to go further – we need more than services – we need community development. It should read:

All Canadians have the right to live in a society that will support a healthy mind and body and to appropriate and timely services that will support these Principles.” (Service Provider, Whitehorse Group)

Revised Principle #1 - All Canadians have a right to appropriate and timely health services that will support a healthy mind, body and spirit.

Principle #2 - The needs of the individual should direct the provision of mental health services.

Participants were asked what they understood this statement to mean and if they agreed with it.

For the majority of groups, the statement *means that needs differ according to the individual and services should be tailored to individual needs* – the person should be at the centre. Services are consumer-driven, not program or staff driven, and the needs of the individual direct the recovery process. A number of participants used the term “one size doesn’t fit all” to reflect their understanding of the statement.

Many of the groups interpreted the statement to mean that *services are flexible and responsive to the full range of individual needs and oriented toward improving overall quality of life*. As such, services will include access to resources to meet physical, social, economic and spiritual needs regardless of the individual’s economic status, level of functionality or race.

A number of people emphasized that “needs” must include basic needs, such as access to healthy food, adequate shelter and the right to employment. These basic needs are seen as critical for improving and maintaining mental health. Participants commented that the most socially and economically disadvantaged consumers lack access to basic services and supports and their living conditions can be appalling. The service system must be responsive to the

“We need the whole range – medication, diet, exercise, yoga, alternatives. They shouldn’t just be for rich people. Many people with mental illness are very poor and they can’t afford any alternative treatments, to eat properly and gym memberships.”

Saskatoon Consumer,
Youth Group

needs of low-functioning consumers who live alone with no family support, and to the needs of street people with mental illnesses. Several participants stated that family physicians do not want to accept these consumers as patients and they (the consumers) have no voice.

"Hope is a priority need – it's essential".

Halifax Caregiver

In the Vancouver multi-cultural group of consumers and caregivers, some thought that too many resources are dedicated to homeless people with addictions and too few to other persons with mental disorders. This concern appears to be related to people feeling that they are competing for limited resources with other groups who have higher needs and represent a highly visible social issue.

Some thought that consumers need more knowledge and awareness to know what services are available and to develop a strong voice. They talked about the need to provide this education early, to children and youth in elementary and high school.

"I shouldn't have to Google for everything on my own".

Vancouver Youth Consumer

Across the groups, participants talked about *the importance of treating the individual as a whole person, not a diagnostic label*. Several said that people are often labelled, diagnostic labels can change, and they are more than their labels.

"If I say I am happy or sad or whatever, it doesn't mean that I am not normal. I am human too – I have normal moods. Not everything I experience is about my illness. I am a human being, not a diagnosis."

Vancouver Youth Consumer

In half of the groups, participants stated directly that *doctors need to listen more to consumers and caregivers*. Several commented that physicians just "hand out medication and send consumers on their way". As one Vancouver youth noted: "The only option I ever hear about is meds and more meds." A number of people suggested that mental health professionals need better training about and should apply more effort to listening to consumers, helping them define their needs and assisting them in finding supports and services.

"Sometimes the only one who will listen to you is the janitor."

Winnipeg Participant,
Aboriginal Consumer Group

Aboriginal consumers talked about the *stigma and discrimination* they encounter in general and how it is related to racism. One said that he cannot disclose he has a mental illness in a job interview because employers will not hire

“Native people are often stereotyped as being mentally ill, no matter what is wrong with us. If we have been drinking or have epilepsy, they think we are mentally ill or take us to jail.”

Winnipeg Participant,
Aboriginal Consumer Group

him for fear he may be violent. Another spoke about the persistent negative stereotyping that Aboriginal people are subjected to.

Some of the participants took the Principle statement to mean the *individual consumer has a right to determine his or her own needs, to be in charge of treatment and to have choices*. As one consumer in Winnipeg put it: “You can say yes or no to treatment or go elsewhere”. However, another responded that it is hard to go elsewhere when there are no services to choose from. This concept – that consumers should be able to determine their own needs and make their own choices about treatment – generated discussion across a number of groups. As the discussions progressed, participants generally acknowledged that while consumers should have the right to define their own needs, they are not always well enough to do so. Several suggested that advanced directives or consumer advocates could help ensure that the consumer’s rights are protected at all times. Furthermore, an advocate could help the consumer define his or her needs and help him or her navigate the service system. Some thought that consumers who are doing well should be used more in the system as peer support persons and advocates, and that there should be more consumers in professional positions in mental health services.

Proposed Statement Changes

Participants agreed with the statement in principle and proposed the following changes and additions.

“I have a problem with the term ‘needs’ – it implies diseases and illnesses as opposed to a strengths-based/wellness approach.” (Whitehorse, Service Provider)

“Put the word ‘appropriate’ here – ‘appropriate mental health services.’” (Montreal Consumer, Anglophone Group)

“It should read: *The needs of the individual will direct the provision of mental health services...‘should’ is a weasel word.*”
(Sudbury Consumer)

“It should say something like: *The needs related to the illness will direct the provision of mental health services, or services will be responsive to the disorder.*” (Sudbury Consumer)

“The statement should read like this: *We affirm that the needs of the individual, as defined by the team, with the individual at the centre of the process, should direct the provision of mental health services.*” (Halifax Caregiver)

Revised Principle #2 - The needs of the individual will direct the provision of mental health services.

Principle #3 - Access to collaborative mental health services in primary health care settings needs to be improved.

Participants were asked what collaborative mental health services meant to them, who should be on the team, and if they agreed with the statement.

Primary health care had to be defined for a number of people who were unfamiliar with the term or were unsure what it meant. For example, the Montreal Francophone group initially thought that hospitals must be the primary health care settings because they were the ones with most of the money, hence offering most of the services.

Across the groups, participants took collaborative mental health services to mean that *professional caregivers construct a network, work together, and communicate and share information.* Most see collaborative care as consumer-focused, and some stated explicitly that they see the consumer as the leader of the team. One youth in Saskatoon thought that the Restorative Justice Model from Aboriginal communities

"It's like having a hand with only one finger [if you don't have collaborative care]. You need all the fingers, or maybe two hands."

Montreal Consumer,
Anglophone Group

"[Collaborative care means] there is no duplication of services and consumers don't have to pick between services because of conflicting schedules – my support group and another service are only available in the same time slot."

Winnipeg Consumer

"Cancer care centres are beautiful places, but mental health settings are still dingy."

Montreal Consumer,
Anglophone Group

would be a good model for the teams. Generally people were supportive of the concept of collaborative care.

One service provider in Whitehorse made the following point about improving collaborative care within the context of primary care settings: "We don't even have a strong primary health care system right now...I would be more interested in talking about collaborative mental health care outside the primary health care system."

Perceived advantages of collaborative care include having easier and equal access to a range of service providers, not having to go through a hierarchy to get services, seamless case management, and eliminating duplication of services.

Some would like to see one location where collaborative mental health services are provided (one-stop shopping). This would be particularly beneficial for low-income consumers with no access to transportation. One group stressed the importance of providing services in a pleasant environment and pointed out the contrast between physical health services and mental health services in this regard.

One youth in Vancouver would like to see the teams use a strength-based rather than deficit-based approach to care, to help consumers build on their strengths and develop confidence and self-esteem.

There was some concern about who would hold the balance of power on the team, as mental health services are still provided in the context of a hierarchical structure where family physicians have decision-making authority. Similar concerns were raised by people across several of the groups in response to the Charter statements, particularly with regard to the existing power imbalance between health care providers and consumers, and in ensuring accountability.

Some of the participants suggested that the way professional education is structured and provided must change to better prepare future health care professionals to work more

collaboratively. For example, interdisciplinary courses should be part of the curriculum in professional schools. Several participants thought that collaborative team members would need specialized training to help them understand other perspectives and communicate effectively with other team members.

Teams who are working with Aboriginal consumers need specific education and training about Aboriginal history and culture to ensure cultural competency. One participant said: “Otherwise, they don’t provide appropriate care to Aboriginal people. This is fundamental.” In one of the Whitehorse groups, some of the participants were residential school survivors. They spoke at length about the ongoing impact of the residential school experience on their people and their communities and stated that most of their mental health problems can be linked directly to the residential school legacy, other abuses and racism. They noted further that many people do not understand the huge impact that these realities continue to exert on health and well being in Aboriginal communities.

When asked to identify which disciplines should be represented on collaborative care teams, the majority of groups listed health care professionals such as psychiatrists and psychiatric residents, general practitioners, nurses and nurse practitioners, dietitians, occupational therapists and pharmacists. One person commented that pharmacists should take a more active role in mental health care, as they know the consumer’s history and should be able to consult with the family physician if they suspect there is a problem. Others would like to see professionals with specialized training in addictions on the teams for consumers with concurrent disorders. Participants in several groups listed psychologists, psychotherapists and social workers as potential team members. In the majority of groups, people would like to see the teams expanded to include a range of service providers and support people.

“I went to a psychiatrist from England and he said, ‘I don’t know what the big deal is about residential schools. We all went to boarding school in England and look at us.’”

Whitehorse Consumer,
Aboriginal Group

“No one wants to talk about racism, but it has a huge impact on collaboration. I had a nurse say to me, ‘They are too stupid to learn so why bother to teach them?’”

Whitehorse Participant,
Aboriginal Group

“The model has to be expanded to include self-help and other alternatives. Sometimes alternatives work as well and are less expensive.”

Halifax Consumer,
Senior Group

Many participants would like alternative, holistic practitioners to be represented on the teams, including those who offer acupuncture, massage therapy, naturopathic care and alternative medicine. Service providers that specialize in exercise and physical fitness were also mentioned by a number of participants who emphasized the importance of physical exercise in enhancing and sustaining mental wellness.

"No one understands mental illness except the mentally ill. Doctors and nurses don't know what it is like."

Senior, Saskatoon Group

In the majority of groups, people saw a need for a representative who could advocate for the consumer and assist him or her in navigating the service system. This could be someone from a peer support group or a family member. Several people suggested that a recovered consumer would be a good advocate and support person.

"Social services needs to be part of the team – the way they treat people is terrible. Every year people have to be "reviewed" [for eligibility]. They are in a panic because they can't work and are afraid they are going to get cut off [from their benefits]."

Youth, Saskatoon Group

Participants in several of the groups suggested that front-line mental health workers, such as community and outreach workers, should be on the teams. Some commented that these workers, who provide high quality, personalized care, are often overworked and underpaid compared to their peers in hospital settings. Other suggestions for team members included school nurses and counsellors, employment services/career counsellors, art and music therapists, recreational counsellors and psycho-social rehabilitation workers. A number also recommended that social services workers be involved in collaborative care teams when consumers are in receipt of social assistance.

In two of the groups, people talked about the importance of involving police and other service providers from the justice system. "They need to be aware of the team, or at least be educated", said a participant in Montreal. "They need to know how to assess and communicate with people in mental health crises, how to call in a professional and who to call." Youth in Saskatoon agreed, noting that many people with mental illness are treated very poorly by service providers in the criminal justice system.

The importance of faith and spirituality was identified by half of the groups, and many participants would like to see representatives from faith communities on the teams. At the same time, they suggested that this issue needs to be handled delicately. While spirituality plays a significant role in health and healing for many consumers, providing them with hope and sense of meaning, it is also associated with some risks. People made a distinction between healthy spirituality, which promotes mental health, and unhealthy religiosity. For some mental illnesses, religiosity is part of the illness. In addition, some faith advisors are uneducated about mental illness and make consumers feel guilty for being ill, or encourage them to go off their medications and rely on prayer to get well.

Three of the groups emphasized the importance of involving Traditional Native Healers, Elders and Medicine People on teams for First Nations or Aboriginal consumers.

Some stated that the traditional Aboriginal model for healing and wellness needs to be more widely used and traditional healers should become the primary caregivers of their own people. It was suggested that any model for mental health care for Aboriginal communities must be developed within the context of what is important for health and wellness. Being out on the land, for example, is calming and healing for many, and it is closely linked to spirituality.

Some participants thought that team membership should vary based on the individual consumer and his or her situation, and that the selection of team members should be guided by consumer needs and preferences.

Proposed Statement Changes

Participants generally liked the statement and would like to see more and better collaborative care. Proposed changes to the statement are as follows:

“Does the statement have to say ‘in primary care settings’?
Most mental health care in the Yukon is through family and

“Our people used to say that the land was our church: that was where we went to pray every day, that was our religion. Everything we do on the land is spiritual.”

Whitehorse Participant,
Aboriginal Group

“The individual should have the right to choose. Just because you are First Nations doesn’t mean you want an Elder on the team. It [the selection of team members] should be relational rather than designated.”

Service Provider,
Whitehorse Group

community support.” (*Service Provider, Whitehorse Aboriginal Group*)

Participants in the Winnipeg Aboriginal Consumer Group commented that the wording is somewhat ambiguous, i.e. “*What does the word ‘improved’ mean exactly?*”

Consumers in the Montreal Anglophone Group agreed they would support the statement if it were strengthened to read: *All Canadians have the right to access timely collaborative mental health services in primary care settings.*

Revised Principle #3 - Access to collaborative mental health services in primary health care settings will be improved.

Principle # 4 - Mental health services need to be flexibly configured to provide access to appropriate providers to meet the varying needs of each individual receiving care.

Participants were asked what flexibility in collaborative mental health services meant to them and if they agreed with the statement.

Most understood the statement to mean that *services are responsive and adaptable to the differences between consumers and their different needs*. As some put it, services are “tailor-made” for the individual. As such, consumers will not have to fit a model or a profile to access services, and treatment will vary depending on the consumer’s needs and path of recovery. Services will change and evolve, shifting in accordance with priorities or the primary need. Others also related the statement to having choices in care and access to a range of services options.

Youth in Saskatoon provided a number of examples of inflexibility in mental health services from personal experience:

“Having to keep an appointment that conflicts with a class I am taking”.

“Telling you to eat lots of fruits and vegetables when you’re on welfare”.

“Sending you all over the city for appointments, especially when you’re poor”.

“Your psychiatrist puts you on heavy meds where you can’t work and your social worker is at the door telling you to get a job”.

Across the groups, people offered a number of specific suggestions for improving the flexibility of mental health services. Several thought that it was important to “match” the mental health professional to the consumer. The two may not be a good fit for a variety of reasons, and consumers should be able to select a care provider that they feel comfortable with. This includes the right to access culturally appropriate services and non-medical services like psychotherapy. Having the right to choose your service provider or providers is important to many consumers and integral to a flexible system of mental health services. In rural areas, as the Saskatoon groups pointed out, this is difficult to implement, because services there are so limited.

Flexibility is related to *continuity of care and follow-up* – it can take a long time for consumers to get well, and service providers have to be prepared to commit to the recovery process with the consumer. Flexibility also means flexible hours for service provision.

Two of the groups spoke about the importance of *flexibility in diagnoses*. The medical model is seen as inflexible in this regard because a consumer has to fit a “Diagnostic and Statistical Manual for Mental Disorder” (DSM) category to get a medical diagnosis of a mental illness.

Participants in two of the groups suggested that the system would have to become more grassroots-driven to be more flexible. They see most of the inflexibility of the existing system as emanating from professionals at the ‘top of the pyramid.’

“Just because you don’t have everything on the list [meet all of the DSM diagnostic criteria], doesn’t mean you don’t have a mood disorder.”

Consumer,
Vancouver Youth Group

Proposed Statement Changes

Participants generally agreed with the statement in principle. However, many thought the statement was poorly constructed and difficult to comprehend as written. One group stated that this statement and all of the Charter statements should use strong, action-oriented words. Two of the groups thought that this statement was the same or very similar to the second statement of the Charter.

The following are proposed changes or additions to the statement:

“The sentence is grammatically complex; it has three clauses. It should say: Mental health services need to be flexible. Providers need to be appropriate. Services need to meet the varying needs of each individual.” (Service Provider, Whitehorse)

“Rephrase it to say: “In order to meet the varying needs of each individual receiving care, mental health services should be flexibly configured to provide access to appropriate providers.” (Participant, Sudbury Consumer/Caregiver Group)

The statement should read as follows: *“...les services de santé mentale doivent être organisés d’une façon plus flexible pour permettre l’accès aux travailleurs et les aidants d’un service personnalisé pour satisfaire les différents besoins de chaque individu recevant les soins.” [“... Mental health services must be organized in a more flexible manner in order to give workers and caregivers access to personalized service that satisfies the unique needs of each individual receiving care.”] (Agreed Montreal Francophone Group)*

It should read: *“We commit to making our services flexible enough to reach out to everyone who needs it or is receiving care.” (Consumer, Montreal Anglophone Group)*

Revised Principle #4 - Mental health services will be flexible to meet the varying needs of each individual receiving care.

Principle #5 - Individuals requiring mental health services and their families are partners in decision-making about their health care.

Participants were asked what they thought of the role of the individual as a partner in collaboration, what the role of the family was and if they agreed with the statement.

Some thought that consumers and family members need access to more information and education about mental health disorders and treatment options to be true partners in decision-making.

Each of the groups struggled with the statement in terms of balancing consumer rights to empowerment and confidentiality with the rights of family members to be informed and engaged partners.

Many people across several of the groups thought that *consumers should be full and equal partners in collaborative care teams*, proactive in their own mental health care, and informed and empowered to make their own choices.

Several consumers commented that they would like their family physicians to listen to them, as they know more about living with their illnesses than do their physicians. Some would like to see consumers in the role of team leaders. Many agreed that while this should be the goal, it is not always achievable. Others suggested that this is why “advanced directives” are so important. Some groups of consumers, including youth, were perceived as more vulnerable and easily intimidated by health care professionals and were therefore especially in need of support and advocacy. In two groups, participants suggested that promoting consumer empowerment takes time and consumers need to be encouraged to “go at their own pace.”

Participants were somewhat divided on the role of the family on a collaborative care team. Some said that it

“Si on était plus éduqué sur la maladie et les choix de traitements, on serait plus partenaires.”

“If we were better educated about the illness and potential choices in treatment, we would become more involved partners.”

Montreal participant,
Francophone Group

“We need appropriate information to make decisions, as much as we are able, about our treatment, just like cancer.”

Halifax Consumer,
Senior Group

“Mental health issues are usually diagnosed after a crash. When you have crashed, you can't really be a participant in your health care. When I went to the psychiatrist, he wanted to know why I was there – I think he was surprised because I hadn't crashed. How can we make sure that this happens more often?”

Saskatoon Consumer,
Youth Group

"My son is in his late 40s and I am in my 70s and what happens when we [his parents] are gone? This worries me."

Halifax Caregiver

"It has taken me 20 years to get an equally respectful relationship with a psychiatrist...I had to fight for that. ...There is always a power difference between the person needing the care and the person providing it. This needs to change."

Halifax Caregiver

"Sometimes families are not supportive – they can be destructive. Family involvement is not appropriate for everyone. As an adult, I would have a problem including family in decision-making."

Sudbury Consumer

depends on the consumer's level of functioning and/or age. For example, some thought that family should make decisions when the individual is incapable of making decisions about care. A number of caregivers commented that parents are excluded from decision-making more often than they are included. Parents often feel blamed for their child's illness. Several participants thought that consumers are sometimes encouraged to exclude family members so that service providers can exercise power or even abuse vulnerable consumers without any family interference. Parents, even parents of adult children, continue to worry about the well being of their children.

Many thought that family members should be involved as full partners. They should be informed and have input into the care of their loved ones. Family members can provide useful information to service providers about the consumer's needs, and many family caregivers would like to see families as equal partners on a collaborative care team. A number of caregivers spoke about the years of effort it took for them to learn how to negotiate the system and advocate effectively for their family members.

Having access to information and support is an issue of importance to youth as well as to parents and other family members. Some consumers talked about being a child of a parent with a mental illness and not getting any information or support. Often they felt guilty, responsible, or unloved. One consumer commented that having more information would have "helped me understand my own illness."

Other participants would prefer to see family members taking more of a supportive role – being there for the consumer, providing love and encouragement, and supporting consumer self-help. Some noted that this could take time. Families often need time to accept the illness and be in a position to actively collaborate in care.

Some were strongly opposed to the idea of automatically including family members as partners in collaborative care.

They thought it would be inappropriate and potentially harmful to the consumer's well being.

Across the groups, most participants concluded that this is a "grey area" and it is difficult to find a perfect balance between consumer and family rights and needs. While it is good to have family support and involvement, it is not always appropriate. Ideally, family members and consumers should be full partners. When put to the test, however, consumer rights have to prevail.

Some suggested that consumers should have to sign consents for family involvement and it should be the choice of the individual if family is involved or not. Others recommended that the term 'personal support people' be used instead of 'family'; that the consumer should be able to choose the people who love and support him or her to be on the team. One participant noted that if the statement says 'family' then it opposes the principle of flexibility. "Family can mean anything", said another. "Anyone you choose can be your family."

Proposed statement changes:

Participants generally agreed with the principle of the statement, but differed somewhat with regard to the role of family and the use of the term "family". Some were concerned about power imbalances between consumers, family members and caregivers, and the physicians. The following represent proposed changes or additions to the statement.

The concept of an equal partnership, at the same level [between consumers, family members and caregivers, and family physicians] should be embedded in the statement.
(Montreal Francophone Group)

The statement implies that the individual 'requires' mental health services. It should read 'desiring' or 'accessing'.
(Service providers, Whitehorse Aboriginal Group)

"From a violence against women perspective, there is often a power imbalance in family relationships. You can't always assume that the family has the person's best interests in mind."

Service Provider, Whitehorse

"Confidentiality - it is there for a reason, but it can be a barrier."

Winnipeg Caregiver

“Maybe instead of ‘family’, it should say ‘*personal support people*’ – the people in your life that love and support you – that you choose to be on the team.” (*Sudbury Consumer*)

Revised Principle #5 - Individuals receiving mental health services are respected partners in their health care. Families, caregivers and/or support networks may also be partners if directed by the individual.

Principle #6 - Individuals should expect to have services that respect their cultural beliefs and preferences.

Participants were asked what this statement meant to them and if they agreed with it.

“The key word is respect – even if you don’t understand, you should respect it [the person’s culture].”

*Participant,
Winnipeg Caregiver Group*

Most interpreted the statement to mean that *service providers should be sensitive to and respectful of the cultural beliefs and practices of consumers*. A number of people emphasized the word “respect.”

In three of the groups, participants said that mental health care providers should have training on cultural differences. One group suggested that cultural diversity training should be provided early, to children in the school system. Some said that people tend to prefer family physicians and psychiatrists from their own culture, although this is not always the case. In Vancouver, participants seemed to feel that cultural differences do not represent a significant issue; problems that consumers experience with providers from other cultures are usually due to language barriers. In Montreal, some Francophone participants thought that translators should be made available where possible for those speaking languages other than English or French.

One young woman in Saskatoon suggested that health care providers from other cultures need training about the North American culture: “My mom was psychotic and she said [told her psychiatrist] that she was going to meet John

Lennon and he didn't know who that was. He just thought it was some guy".

Six of the groups talked about the need to respect spirituality and faith traditions, as well as cultural beliefs and preferences. Several people mentioned that they are unable to share their religious beliefs with their health care providers for fear of being assessed as delusional. Vancouver youth, in particular, had a broad range of spiritual belief systems, from Christianity to Wicca, and they all said that they keep their religious beliefs to themselves.

Across several of the groups, participants suggested that the statement represents an ideal, which might be hard to accomplish in practice. Some wondered how all mental health care providers could possibly be educated about the range of cultural beliefs. However, one woman commented that areas with a lot of cultural diversity will also have cultural diversity in the workplace, and these people could educate their co-workers.

Generally, participants supported the statement, but they cautioned that good judgment is needed. Cultural and religious beliefs and preferences should be respected unless they are harmful, and it is sometimes difficult to distinguish between cultural and in particular, religious beliefs and mental illness.

Proposed statement changes

It should read this way: *"Individuals should expect to have services that respect and understand their faiths, cultural practices and beliefs."* (Participant, Winnipeg Caregiver Group)

It should read: *"Individuals have the right to have, or will receive, services that respect their cultural beliefs and preferences."* (Sudbury Consumer)

"Don't like the word 'should', it needs to be stronger... 'will have services that.'" (Participant, Whitehorse Aboriginal Group)

"They ask you things like 'Do you talk to God?' as an indicator of illness. I do talk to God because I am a Christian and I said 'yes' and they put me on anti-psychotics for a year and I have depression, not psychosis."

Vancouver Consumer,
Youth Group

“Don’t like ‘should’. It should read ‘Individuals will have access to’ and also should include ‘beliefs and values.’ And it should include *spirituality*.” (Service Providers, Whitehorse Group)

“Change the word ‘respect’ to ‘honour’. It supports the dignity of the client more”. (Participant, Winnipeg Aboriginal Group)

Revised Principle #6 - Individuals expect to have services that respect their cultural and spiritual beliefs and preferences.

Principle #7 - We believe that effective collaboration requires:

- a) mutual respect and support;**
- b) willingness to learn from each other;**
- c) knowledge of the skills and competencies of fellow members of the interdisciplinary team;**
- d) effective communication;**
- e) clearly articulated and mutually agreed upon treatment goals;**
- f) shared decision-making;**
- g) clear definitions of roles and responsibilities; and**
- h) mutual accountability.**

Participants were asked if any of the points were unclear and if they agreed with the statement.

The statement was clear to most of the participants, and they were generally in agreement with it. Some said it was the best statement “in the bunch.” Others suggested that it be put higher in the document, after the third statement, because it explains what effective collaboration is.

Five of the groups expressed some concern about mutual accountability and how team members could be held accountable to each other, including the consumer. They

would like to see mechanisms developed to ensure accountability. Some thought that there should be a system in place to file complaints. One youth in Saskatoon suggested that team members should have to meet the requirements of the Charter or be taken off the team. A youth in Vancouver suggested developing a list with consumer reviews of physicians. It could be posted on a Website – rateyourdoctor.com. Another youth in Vancouver added that good doctors need to be recognized and consumers should acknowledge them, perhaps through something like an annual Patients' Choice Award. A consumer in Sudbury expressed concerns about financial accountability in relation to ensuring that the service represents good value for the money invested.

The Saskatoon youth participants would like to see some reference to the importance of treating people with compassion, especially with regard to people who are non-compliant or difficult. Halifax seniors were somewhat concerned about the lack of reference to family support; they want family support to be encouraged, but recognize that ultimately it is the consumer's choice. In a couple of the groups, participants disliked the emphasis on treatment, as in 'treatment goals'.

Two groups raised concerns about confidentiality issues, but for different reasons. In Montreal, the Francophone group agreed that information about the consumer's mental health and mental illness should be shared among collaborative care team members, but not with other health care professionals. This concern appears to be related to the stigma that consumers continue to experience within the health care system and is reflective of the comments made by Saskatoon youth in response to the first statement of the Charter.

One of the groups in Whitehorse emphasized the importance of collaborative team members maintaining client confidentiality and stressed that roles of team members will

"Quand tu vas à l'hôpital, te faire traiter pour autre chose que des problèmes de santé mentale, et qu'ils ont la liste de médicaments de santé mentale, ils te traitent d'une façon absolument différente des autres." ["When you go to the hospital to be treated for problems unrelated to mental health, and they have the list of medication that treats mental illness, they treat you differently from the others."]
Montreal Consumer,
Francophone Group

have to be very clear because people can overstep boundaries.

Proposed statement changes:

“Should add something like: *If they are not prepared to meet the requirements of the Charter, they are off the team.*” (Saskatoon youth)

“Mutual accountability is difficult – to what degree can people be held accountable to each other? What about liability issues? It should read: *Mutual accountability to each other within the team.*” (Halifax caregiver)

Add “*face à leur rôle*” [“toward their role”] to mutual accountability. (Montreal Francophone Consumer Group)

“Don’t like the word ‘*treatment*’ – it is about doing something to, instead of with, someone. Use the word ‘helping.’ Or take it out and just use the word ‘goals’”. (Service Providers, Whitehorse Group)

“[I would eliminate] ‘*clearly articulated and mutually agreed upon treatment goals*’...even a husband and wife may not agree on the type of treatment. The goals might be the same, but the way of getting there might differ.” (Halifax senior)

“Add the words ‘*improving relationships*’ and ‘*shared vision*’” (Service Provider, Whitehorse Group)

There needs to be something in the statement about *equity of access to services and breaking down barriers due to age, gender, etc.* (Service Provider, Whitehorse Group)

There should be something in the statement related to *maintaining client confidentiality.* (Whitehorse Service Providers and Montreal Francophone Group)

“It should say ‘cultural competency is required for working with First Nations populations’”. (Service Provider, Whitehorse Aboriginal Group)

“Add ‘honest acknowledgement of the person’ ” (Sudbury Consumer)

Principle #7 - Remained unchanged.

Principle # 8 - The range of service options for persons requiring mental health services should be communicated to the consumers, families and caregivers.

Participants were asked what range of options meant to them and if they agreed with the statement.

The majority of participants understood “range of options” to mean *the services and supports that are available to people*. Many emphasized how important it is to communicate these to consumers and caregivers, because people are often unaware of the options. It was pointed out that the only way you can know if you are getting what you need is if you know what is available. Some said that knowing the options will also allow people to make choices as opposed to being ‘stuck’ with one service option, which may not be a good fit. Communicating the range of service options will help to reduce duplication and overlap, and bridge the gap between medical and non-medical services. It was suggested that providing information about service options might promote early identification and intervention.

“Some people don’t even know that they need services. If they got the information about the range of service options, they might realize that they need services or be interested in accessing services.”

Participant,
Winnipeg Caregiver Group

For most, “range of options” means a *full range of options relating to education, services and supports*. This includes information about self-help, peer advocacy and support, and non-traditional alternative interventions, including spiritual support. Two groups suggested that information about basic needs services should also be communicated to consumers, such as how to access income assistance programs, obtain insurance, etc. Vancouver youth would

like access to more information about scholarships, bursaries and employment subsidy programs and they would like to be able to access this information in one place, like a Web site.

Across the groups, many said that family physicians do not communicate service options to consumers and family members, and are often unaware of service options outside traditional medical interventions. Consumers and family members would like access to written materials about resources and service options. These should be “up front and visible” in family physician offices and pharmacies, and written in clear, accessible language. Suggestions for the specific types of information that need to be provided include:

- ✓ Information for families about symptoms, diagnoses and whom to contact.
- ✓ Information for consumers about a range of options for symptom management (medical and non-medical).
- ✓ Information about medications and their effects and side effects, and the range of medication options.
- ✓ Information about support groups.
- ✓ Information about other services and resources, such as income, education and employment assistance programs.
- ✓ Realistic information for youth (free of social judgment) about the dangers of street drug/alcohol use and driving when on psychiatric medications.

In three of the groups, participants said that stigma continues to operate as a barrier to knowledge and awareness. Four of the groups would like more public education about mental illness, mental health and mental health services. Several people noted that the media perpetuates a lot of myths and that more accurate information and realistic portrayals of persons with mental illness are needed in the media. For example, there should be information about mental health and mental illness on the

television channels that youth watch regularly, such as Much Music and TSN.

A number of people also spoke about the importance of education in the schools. Because of the stigma associated with mental illness, children and youth will not seek help, and those with mental health problems are treated very badly by their peers. They would like to see education on mental illness and mental health included in the school curriculum, perhaps integrated with information about general health and wellness. Some suggested that this information needs to be provided early, in elementary school, and that there are good, age-appropriate teaching resources available for younger children.

The Saskatoon groups discussed the difficulty of communicating a range of options in rural areas, where services are limited and there is often a lot of stigma. One participant suggested that television would be an effective means of disseminating information in rural areas, as there are only two channels and “50% of the people would be sure to see the ads.”

Proposed statement changes:

Participants generally agreed with the statement, and many thought that it was very important. They proposed the following statement changes or additions:

“The statement is not strong enough – it should read: *It is essential to articulate and communicate the full range of service options...*” (Halifax Caregiver)

“This is very, very important – ‘should’ needs to be changed to ‘will be communicated’ or ‘is communicated’”. (Sudbury Consumer)

“Rewrite the statement to include the importance of *informing and educating people about mental health services, as*

“There are so many ads about cancer and giving people hope, but wht about people with schizophrenia and other disorders?”

Youth Consumer,
Saskatoon Group

“I think high school is too late – they should go in younger – I tried to kill myself when I was 10.”

Youth Consumer,
Saskatoon Group

well as communicating with them. (*Montreal Francophone Group*)

“Add ‘network’ – ‘consumers, families, caregivers and network’” (*Service Provider, Whitehorse Group*)

“Should add: ‘education and support options’ as well as ‘service options’”. (*Sudbury Participant, Consumer/Caregiver Group*)

“Add ‘developing, articulating and communicating the range of options.’” (*Consumer, Montreal Anglophone Group*)

Change the ending to read: “for persons on the path to mental and all-around wellness and recovery.” (*Consumer, Montreal Anglophone Group*)

Revised Principle #8 - The range of service and support options for persons receiving mental health services will be communicated to the consumers, families and caregivers.

Principle #9 - We will speak with one voice to government about the need for policies, legislation and funding mechanisms to facilitate access to collaborative mental health care.

Participants were asked if they agreed with the statement.

The majority agreed with the statement and several commented that they strongly support the idea of speaking with one voice. However, some wondered if it is really possible to have one voice. A participant in Winnipeg suggested that while it may not be possible to speak with one voice, there could be many voices speaking in unison.

In five of the groups, people expressed some concern about one voice being the only voice and therefore not fully inclusive. In Montreal, the Francophone group was particularly uncomfortable with the statement because as translated, it said “the only (seule) and same (même) voice”.

They were supportive of the idea of the same message being communicated to government, as long as the voice is inclusive of varying perspectives in the mental health and mental illness communities. Participants acknowledged the potential power of one voice and they want assurances that individual and marginalized voices will not be overshadowed and will continue to be heard.

Some participants said they would like to have ongoing input so that if the government does adopt the Charter, policies and funding mechanisms will be changed in ways that really meet consumer needs. They want ongoing dialogue and some way to ensure accountability.

Proposed statement changes:

“It should read: ‘*establish collaborative mental health care*’ as well as ‘*facilitate collaborative mental health care*’ because it doesn’t exist yet – pockets exist but it still has to be developed.” (Halifax Caregiver)

“Add the word ‘*integrated*’ in front of ‘*collaborative*’.” (Consumer, Montreal Anglophone Group)

“Add ‘*a shared vision*’, ‘*one voice and a shared vision*’.” (Service Provider, Whitehorse)

Say “*Nous parlerons au gouvernement, d’une même voix...*” [“We will speak with a unified voice to government.”] (Montreal Francophone Group)

Add a 10th point: “*We are committed to broadening the circle intentionally to seek other views and voices.*” (Agreed by all, Whitehorse Aboriginal Group)

Add a 10th point: “*All partners will focus on the individual and not the diagnosis.*” (Sudbury Consumer)

Principle #9 - Remained unchanged.

“That scares me a lot...if the circle is not more inclusive. The voice will be powerful and the government may listen to them and discount other voices. The concern is that this voice becomes the only voice...don’t limit the size of the coalition and don’t give government the right to discount other, more marginalized voices.”

Service Provider,
Whitehorse Aboriginal Group

General Comments

The term 'dignity' is missing from the Charter. Stigma is equated with shame and people tend to avoid situations that produce shame. Dignity is very important when talking about mental health issues so that the sense of shame is not present. *(Participant, Winnipeg Aboriginal Group)*

There needs to be something in the Charter about being open to new learning and new information as it comes along. Something that suggests that the Vision will evolve as knowledge emerges and is a work in progress. *(Halifax Senior)*

How can an approach be truly patient-centred when people can be forced to accept care against their will? It is the only area of health care where services can be forced on you. *(Sudbury Consumer/Service Provider, Whitehorse)*

There is no reference in the Charter to persons with a primary diagnosis that is not a mental illness, e.g. people with developmental delay. *(Sudbury Consumer)*

APPENDIX III - PARTICIPANT FEEDBACK: CONSUMER, FAMILY AND CAREGIVER TOOLKIT

Seven of the 14 consumers, family members and caregivers groups participated in one-hour discussions about two proposed toolkits. These one-hour sessions took place in Halifax, Montreal, Sudbury, Winnipeg, Saskatoon, Whitehorse and Vancouver. This feedback includes suggestions and recommendations about two Toolkits for consumers and caregivers: one for personal care and participating as an equal partner on the collaborative care team, and one for participating at the governance level. Items are presented in the order of frequency of response (number of groups who made the suggestion/recommendation). A consistent theme throughout all of the discussions is the need for all information to be provided in clear, accessible language.

A. Personal Care/Participating as an Equal Partner on a Collaborative Care Team

1. Information about the full range of service and support options

All of the groups indicated that they would like to have access to information about a full range of service and support options, inclusive of but not limited to conventional medical interventions. They want to know what is available, how to access it, how much it will cost, and how to negotiate the system. Currently, it is not easy to obtain this information: consumers have to seek it out themselves, leaving those who are very ill or otherwise without personal resources at a distinct disadvantage. This is also an important need for family members who often don't know how or where to find services on behalf of the consumer or for themselves. Participants stressed that information needs to be made available in accessible language. *"They give you*

pamphlets, but it isn't in layman's terms – it's too complicated".
(Saskatoon Youth Participant)

Information that consumers thought would be helpful to consumers and caregivers:

- ✓ Information about psychology, social work, therapy/support and where to go for therapy.
- ✓ Information about non-traditional alternative care: for example, yoga, meditation, diet, spiritual resources (such as clergy).
- ✓ Information about accessing traditional Aboriginal practices and Healers. For example, providing a copy of the medicine wheel for self-assessment. *"It isn't just for First Nations, it is for everyone. The whole human race."* (Whitehorse Aboriginal Participant)
- ✓ Information on coping skills.
- ✓ Information about self-help/peer support programs.
- ✓ Opportunities for volunteering and provision of training in providing peer support.
- ✓ Information about what is covered by provincial health care and what isn't, and the costs of services that aren't covered (to determine affordability).
- ✓ Information about helplines and mobile crisis services.
- ✓ How to find information on the Internet.
- ✓ How to negotiate the system – information should be available on one sheet captured in a few points.

Participants offered suggestions about how to provide information:

- ✓ Written materials – for example, pamphlets, brochures, handout sheets. Handout sheets could be developed on specific topics, such as coping skills, information about support groups, or how to negotiate the system. Written materials should be up front and readily available in physicians' offices and in pharmacies.

- ✓ Centralized resource - have one place to go to find information about the range of support options and how to access services; have access to a well-informed person who serves an information clearinghouse function.
- ✓ Provide a list of relevant Web sites.
- ✓ Provide a list of health information telephone numbers.

2. Realistic information about the illness, treatment and the process of recovery

Both consumers and caregivers would like more access to information about mental illness, treatment and recovery. Families want information about symptoms, diagnoses, and other related issues to help them understand better what the consumer is experiencing and what his or her needs are. In particular, people want clear, accessible information about medications in order to assist consumers in making effective decisions about their own care. Participants stressed that they need “realistic” information – information that is factual, open and user-friendly and includes expected outcomes for recovery, side effects of medications, the real risks of using street drugs or driving a vehicle, etc. Youth noted that they may choose to use street drugs such as marijuana, drink alcohol, or drive and they need accurate information, free of social judgments, about the real risks of these behaviour choices.

Participants would like the following types of information about medication and lifestyle choices:

- ✓ Information about what medications there are, which disorders they treat (sometimes they are used for more than one disorder) and their effects and side-effects to help consumers make informed decisions about medications; for example, provide a list of pros and cons and accurate information about the long-term effects of specific medications.

- ✓ Information about the effects of street drugs (when ill and/or taking prescription medications).
- ✓ Real risks of driving while taking medication.

Several suggested that information about pharmaceuticals be provided to consumers and caregivers in written form (e.g., hand-outs).

Participants also want information about the process of recovery – how long it will take and what it will involve. They also want to be educated about early signs of relapse.

“ I need information about what the realistic outcome for my life is – where I am on the continuum of recovery, where I need to go (the goal) and what strategies we (me and the team) are going to use to get me there”. (Vancouver Youth Participant)

Caregivers would like information about how to help the consumer, e.g. how to encourage him or her to participate in self-help. Caregivers suggested that it is just as important that they get education on what not to say or do when trying to help the consumer so that their support efforts are not counter-productive.

3. Information about the roles and responsibilities of all collaborative care team members

Consumers and caregivers would like information about the different service providers on the team, their roles and responsibilities, and skills and competencies, including what they can and cannot do.

4. Education and support for consumer self-advocacy.

Several of the groups suggested that consumers need education and support for self-advocacy and personal choice, to help them feel more empowered and act assertively. This could include information and assistance for developing advanced directives for care.

5. Information about how to find/establish an advocate/support person or network

Several groups would like information about consumer advocates and how to access them. Advocates/support people may include family members, support groups, or other. One group in Whitehorse emphasized that advocates need to have “teeth and some pull” and that First Nations/Aboriginal consumers must have access to a First Nations/Aboriginal advocate.

In Vancouver, one youth recommended the approach currently used for persons diagnosed with HIV/AIDS. When people with HIV/AIDS are first diagnosed, they go through an orientation with a peer “buddy”, who shares his or her experiences with the illness and guides the consumer through the service system.

6. Information about ways to ensure accountability of service providers and monitor service quality

Consumers and caregivers raised some concerns about the concept of mutual accountability for collaborative care teams and how it could be ensured in practice. They would like to have clear mechanisms for ensuring the accountability of team members and to be informed about how these mechanisms work. For example, it was suggested that there should be one collaborative plan that everyone is familiar with and follows, and that all team members should be aware of what others are doing within the plan. All plans should be developed based on Charter Principles, and if team members are not prepared to meet the requirements of the Charter, they should be “off the team”.

Another means proposed for consumers to oversee the accountability of health professionals is the establishment of a peer review of family physicians. *“We should have a list with reviews of mental health doctors, like a consumer report on the Web – they do it for teachers and professors –*

rateyourdoctor.com" (Vancouver Youth Participant). One participant suggested that consumers could recognize good doctors through an annual Patient's Choice Award.

7. Information and support in dealing with family members

Some consumers have difficulty with their family around the issue of mental illness due to feelings of shame and stigma. Consumers would like more information about how to deal with relationships with family members.

8. Material that encourages people to continue on the path of recovery

Consumers and caregivers need information about the process of recovery. The material should be realistic about the frustrations and challenges, but promote optimism and encouragement to continue through the process. It should emphasize that the illness will not improve and may get worse without help.

9. Information about financial support, employment and education

Consumers would like information about sources of financial support and how to access them – welfare, disability supports, etc. Information about accessing scholarships or bursaries for education and employment related services and supports would also be useful.

Such information could be provided in one location, such as a Web site, where consumers could research all of the support services and discover who offers them, including: income support, employment and education services. Practical information, such as how to look for a job, how to prepare a resume, should be included.

10. Access to stories of recovery

Consumers would like to see stories of recovery and examples of positive role models – people who have successfully recovered from their mental illness, including the strategies people have used to deal with the effects of medications.

B: Participating as an Equal Partner in Governance

1. Support and assistance for full inclusion as an equal partner

Consumers were somewhat concerned about becoming “token” members of boards or committees. They also stressed the importance of consumer empowerment for participation as a full and equal partner on the team. Many consumers feel disempowered and suggested that they would be uncomfortable or intimidated sitting on a board or steering committee. *“I would not want to be there on the board as a “token” consumer – I don’t have their specialized skills and I would be concerned about how I could sit there without feeling lesser than, regardless of their good intentions”.* (Vancouver Youth Participant)

Consumers recommended that boards commit to taking the time required to explain board processes to consumer members and to make them feel welcome. In Whitehorse, participants suggested that the board itself could benefit from a toolkit that describes how to help consumers feel comfortable. Information about how boards and committees work and how decisions are made, not just locally, but also provincially and nationally would be useful.

Some consumers agreed that they might feel more comfortable being invited to sit on a board committee that

matches their personal interests before moving to a position as a director of a board. To reduce feelings of tokenism and promote consumer empowerment, it was suggested that several (if not most) of the seats on boards or committees be designated for consumers. Furthermore, consumers would like other board members to disclose the fact that they are consumers, if they are. This would promote a sense of kinship, equality and trust.

2. Ensuring accountability

Consumers and caregivers raised the issue of ensuring the accountability of boards and committees. It requires continuing dialogue about the quality of the service system - to make certain that it is doing what it is supposed to do and is continually improving.

3. Information about program evaluation

Information about program evaluation would be useful for consumers or caregivers who want to sit on boards or committees. Some participants cautioned, however, that consumers, family members and caregivers would have to be more knowledgeable or educated in order to evaluate programs and services. Indicators for measuring the success of a collaborative care team from a consumer perspective include the following:

- ✓ The service was provided and met both immediate and long-term needs, with more emphasis placed on long-term needs.
- ✓ The quality and not just quantity of service is reviewed – not just “if” someone got services and follow-up, but the quality of the service provided is evaluated.

Quality questions include:

- ✓ Was the person treated like a human being? This includes feeling heard.
- ✓ Does the person feel empowered and responsible for his or her own mental health?
- ✓ Does the person feel better and is functioning better than before service was initiated?

This includes:

- ✓ Symptom reduction or relief
- ✓ Stable mood
- ✓ Fewer life crises
- ✓ Ability to work or go to school
- ✓ Coping skills

“If I am eating and sleeping better, have coping tools, am feeling more social, the program is a success. If I am feeling more depressed, ashamed, more isolated, then the program is not a success.” (Vancouver Youth Participant)

4. Remuneration for participating

Some consumers indicated that they should receive payment for participating on boards or committees.





NATIONAL CONSULTATIONS

1. Consumers, Families and Caregivers
2. Expert Advisory Forums
3. Online Survey
4. Synthesis Report

Other CCMHI Resources

RESEARCH SERIES

- Barriers and strategies
- Framework
- Annotated bibliography
- Better practices
- Canadian initiatives
- Policy review
- International initiatives [unpublished internal document]
- Health human resources
- Prevalence of mental illness and service utilization
- Interprofessional education
- Aboriginal mental health [unpublished internal document]
- The state of collaborative mental health care

TOOLKIT SERIES

- Collaboration between mental health and primary care services
 - Aboriginal peoples
 - Children and adolescents
 - Ethnocultural populations
 - Individuals with serious mental illness
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- Working together towards recovery
- Pathways to healing for First Nations people
- Strengthening collaboration through Interprofessional education

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