

The Senate



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OUT OF THE SHADOWS AT LAST

Transforming Mental Health, Mental Illness and Addiction Services in Canada

Final Report of
The Standing Senate Committee on Social Affairs, Science and Technology

The Honourable Michael J.L. Kirby, Chair
The Honourable Wilbert Joseph Keon, Deputy Chair

May 2006

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Final Report on
Mental Health, Mental Illness and Addiction

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AND ADDICTION SERVICES IN CANADA

Chair

The Honourable Michael J.L. Kirby

Deputy Chair

The Honourable Wilbert Joseph Keon

May 2006

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ORDER OF REFERENCE

Extract from the *Journals of the Senate* for Thursday, October 7, 2004:

The Honourable Senator Kirby moved, seconded by the Honourable Losier-Cool:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness.

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee; and

That the Committee submit its final report no later than December 16, 2005 and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006.

The question being put on the motion, it was adopted.

Extract from the *Journals of the Senate* for Thursday, October 20, 2005:

The Honourable Senator Kirby moved, seconded by the Honourable Senator P  pin:

That, notwithstanding the Order of the Senate adopted on Thursday, October 7, 2004, the Standing Senate Committee on Social Affairs, Science and Technology, which was authorized to examine and report on issues arising from, and development since, the tabling of its final report on the state of the health care system in Canada in October 2002 (mental health and mental illness), be empowered to present its final report no later than June 30, 2006, and that the Committee retain all powers necessary to publicize the findings of the Committee contained in the final report until October 31, 2006; and

That the Committee be permitted, notwithstanding usual practices, to deposit any report with the Clerk of the Senate, if the Senate is not then sitting; and that the report be deemed to have been tabled in the Chamber.

After debate,

The question being put on the motion, it was adopted.

Extract from the *Journals of the Senate* of Tuesday, April 25, 2006:

The Honourable Senator Keon moved, seconded by the Honourable Senator Stratton:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness;

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh and Thirty-eighth Parliaments be referred to the Committee;

That the Committee submit its final report no later than June 30, 2006 and that the Committee retain all powers necessary to publicize the findings of the Committee until September 30, 2006; and

That the Committee be permitted, notwithstanding usual practices, to deposit any report with the Clerk of the Senate, if the Senate is not then sitting; and that the report be deemed to have been tabled in the Chamber.

Paul C. Bélisle
Clerk of the Senate

SENATORS

The following Senators have participated in the study on mental health and mental illness of the Standing Senate Committee on Social Affairs, Science and Technology:

The Honourable Michael J. L. Kirby, Chair of the Committee

The Honourable Wilbert Joseph Keon, Deputy Chair of the Committee

The Honourable Senators:

Catherine S. Callbeck

Andrée Champagne

Ethel M. Cochrane

Joan Cook

Jane Mary Cordy

Art Eggleton

Joyce Fairbairn, P.C.

J. Michael Forrestall

Aurélien Gill

Marjory LeBreton

Viola Léger (retired)

Yves Morin (retired)

Lucie Pépin

Brenda Robertson (retired)

Marilyn Trenholme Counsell

Ex-officio members of the Committee:

The Honourable Senators: Jack Austin P.C. or (William Rompkey) and Noël A. Kinsella or (Terrance Stratton)

Other Senators who have participated from time to time on this study:

The Honourable Senators Di Nino, Dyck, Johnson, Kinsella, Lynch-Staunton, Mercer, Milne, Murray, Pearson, St.Germain, Stratton and Tardif.

ACKNOWLEDGEMENTS

The Committee wants to publicly acknowledge the enormous assistance it has received during the past two years from those who have worked so hard in helping the Committee to produce its reports on Mental Health, Mental Illness and Addiction.

In particular, the Committee wants to express its deep appreciation to the following people:

Dr. Howard Chodos and Mr. Tim Riordan Raaflaub of Parliamentary Information and Research Service, the full-time research staff of the Committee, have been deeply involved in all drafts of the reports that the Committee produced during this study. Mrs. Odette Madore was a key researcher on our first three reports on Mental Health and Dr. Nancy Miller Chenier was heavily involved in this final volume. The Committee is also grateful to the numerous other researchers from the Parliamentary Information and Research Service who worked on many of the individual chapters in this report. Without all their extraordinary help and commitment these reports would not have been completed in such a short time, nor in such a competent manner.

Josée Thérien, the Committee Clerk and her assistant, Louise Pronovost, were responsible for organizing all the meetings the Committee held on Mental Health, Mental Illness and Addiction, including scheduling the appearances of all the witnesses, for overseeing the translation and printing of all the reports, and for responding to thousands of requests for information about the Committee's work and for copies of the Committee's reports.

Dr. Duncan Sinclair, the former chair of the Health Services Restructuring Commission of Ontario, who without failure, gave generously of his time. His expertise, support and advice was welcomed and appreciated throughout the Committee's study.

We also want to thank the staff of each of the members of the Committee, who have had to endure a substantially increased work load over the past two years.

Thanks is also owed to Steve Lurie, for his extraordinary assistance on many of the technical aspects and cost estimates used in the report.

Also to Dr. David Goldbloom for his wise advice and counsel.

The Committee is indebted to Sheryl Pedersen, author of "Emmy's Story," which comprises the epilogue of this report.

To all of these people, we express our heartfelt thanks for a job very well done.

The Committee worked long hours over many months, requiring the services of a large number of procedural, research and administrative officers, editors, reporters, interpreters, translators, messengers, publications, broadcasting, printing, technical and logistical staff who ensured the progress of the work and reports of the Committee. We wish to extend our appreciation for their efficiency and hard work.

In *More for the Mind*, a study of psychiatric services in Canada, the Canadian Mental Health Association said:

In no other field, except perhaps leprosy, has there been as much confusion, misdirection and discrimination against the patient, as in mental illness... Down through the ages, they have been estranged by society and cast out to wander in the wilderness. Mental illness, even today, is all too often considered a crime to be punished, a sin to be expiated, a possessing demon to be exorcised, a disgrace to be hushed up, a personality weakness to be deplored or a welfare problem to be handled as cheaply as possible.¹

These words were written nearly half a century ago. Yet the more than two thousand personal stories submitted to the Standing Senate Committee on Social Affairs, Science and Technology by Canadians living with mental illness, and their families, make clear that these words continue to ring true.

It was difficult emotionally for Committee members to hear these stories. Listening to them, and reading them, had a profound effect on every one of us. As the months passed, they began to tear at our souls.

Committee members could relate to these stories because of their own personal experiences. Like any group of a dozen Canadians, we too have experienced the impact of mental illness in our families: a sister-in-law who has schizophrenia, a nephew who committed suicide, a daughter who battled anorexia for several years, a sister who lives with severe depression and has been in and out of psychiatric hospitals frequently; it is rare that a family has not been affected.

Indeed, it is this personal experience that has caused Committee members to regard our work on this report as much more than just another policy study: to us, it is truly a calling.

We know how difficult it will be to improve the lives of people living with mental illness. We know it will be tougher still to change deep-seated public attitudes and reduce the stigma and discrimination they face. To put each of them on the road to recovery will be an extraordinary challenge.

Yet we are optimistic that the time has come when meaningful change can, and will, be made. From coast to coast we have met politicians, government officials, mental health service providers and professionals, and many, many ordinary Canadians, who are willing to help make change a reality, to help bring people living with mental illness into the mainstream of Canadian society.

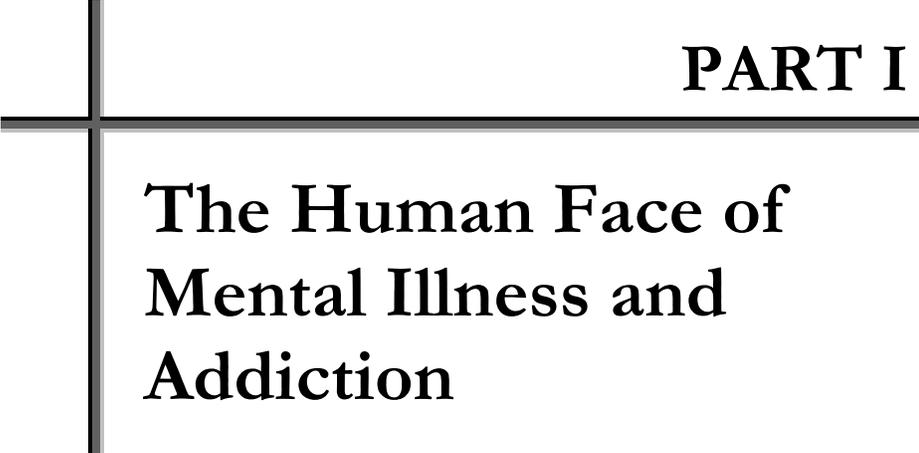
¹ Canadian Mental Health Association, (1963) *More for the Mind: A Study of Psychiatric Services in Canada*, Toronto, p. 1.

We ask the readers of this report to join with us as, together, we work to transform mental health, mental illness and addiction services in Canada and to bring mental illness *Out of the Shadows at Last*.

To the people of Canada, I say welcome us into society as full partners. We are not to be feared or pitied. Remember, we are your mothers and fathers, sisters and brothers, your friends, co-workers and children. Join hands with us and travel together with us on our road to recovery.

Roy Muise — 9 May 2005 - Halifax²

² 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.



PART I

**The Human Face of
Mental Illness and
Addiction**

CHAPTER 1: VOICES OF PEOPLE LIVING WITH MENTAL ILLNESS



One of the most troubling stories heard by the Committee came from a young woman we had the opportunity to meet during our time in St. John's, Newfoundland. In tears, Helen Forristall told her story of being diagnosed with depression:

The purpose of this chapter is to share with readers some of the stories we were told – in the words of those who told them. We hope that these stories will affect readers as they have every member of the Committee.

I do not like to admit it. I am ashamed and humiliated and I still have to work on that, but I am a mental illness consumer and I do take strong offence to stigma.

[...]

My doctor told me I had a sick brain just like somebody else would have a sick heart and that is fine and well in a doctor's office, but in society, that does not work. People tell me to, "Snap out of it," and "Think happy thoughts." They recommend books to you and they lay this guilt trip on me, such as, "You are too young to be depressed," and, "You have nothing to be depressed about..." Again, I did not choose this. If I had breast cancer, nobody would question me.

When I came to my employers and told them that I was depressed, they said, "Well, you will have to prove that." I said, "I intend to. I have a note from a psychiatrist that says so. If you would like to see my purse, I have lots of pills that I have to take and I have to suffer through."

I also have to suffer through the indignity of being looked down on and it bothers me a great deal, so it is difficult to sit here [at the public hearing]. I find myself hiding behind my hair when there is a picture being taken because I still deal with the shame every day.

I wanted to say that I left my job last year sobbing [...]. I worked with the federal government. I left my job, July 9. I have not been back. I am on the status of leave without pay, leave undetermined. I have to fill out questionnaires monthly to prove that I am still mentally ill.

I had to beg my GP to have an appointment with a psychiatrist. I begged him, I pleaded with him and his response was, "Yes, well, he has 600 active patients. He is getting old and you do not really need this. Just keep on taking your drugs..."

[...]

I am in a program in Merchant House for which I had to wait six months to get an interview to be accepted into the program. I am glad to say I am in the

program, but my counsellor has recommended that I go into group therapy, for which I am on two waiting lists. I am sixteenth on one list and she did not want to give me the number of the other list because it is much too long. She told me the program is supposed to last six months, but it ends up being two years or so because of the waiting lists.

[...] I have lost family and friends because they are afraid. The fear in this case is ignorance and I just have to deal every day with suicidal thoughts, medication, therapy and psychiatrists. It is not an easy road.

I would do anything to have breast cancer over mental illness. I would do anything because I [would] not have to put up with the stigma.³
— Helen Forristall

Helen's is a disheartening example of the lack of support from friends, family, co-workers and employers that many people living with mental illness face every day. Hers is also an example of the difficulty accessing mental health services all too often experienced by these individuals.

I have lost family and friends because they are afraid. (...)

I would do anything to have breast cancer over mental illness. I would do anything because I [would] not have to put up with the stigma.

— **Helen Forristall**

1.1 INTRODUCTION

Over the past year, the Standing Senate Committee on Social Affairs, Science and Technology has received more than two thousand submissions from all across Canada on the subject of mental health, mental illness and addiction. Hundreds of Canadians shared heartbreaking stories that revealed to the Committee the true state of Canada's mental health, mental illness and addiction "system."⁴

Through two online consultation processes, as well as hearings in every province and territory, the Committee heard from those who are most directly affected by Canada's mental health system, people who live or lived in the past with a mental illness or addiction. The purpose of this chapter is to share with readers some of the stories we were told — in the words of those who told them. We hope that these stories will affect readers as they have every member of the Committee.

The members of the Committee have come to recognize the reality that profound change is essential if persons living with mental illness are to receive the help they need and to which they are entitled. We trust that readers of this report will reach the same conclusion.

³ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴ As documented in the Committee's interim reports (November 2004), the extensive fragmentation of the delivery of mental health supports and services in Canada precludes speaking in any meaningful sense of a coherent and integrated mental health system. Throughout this report the term system is used simply to indicate that there is a multiplicity of types of services and supports, both formal and informal, available to people living with mental illness and addiction, no matter how insufficient they may be.

1.2 EXPERIENCES WITH MENTAL HEALTH AND ADDICTION SERVICES

Although the Committee did hear from people who managed to find the supports and services they needed, their stories, sadly, were far outnumbered by those from others about their ongoing struggles to get the help they need to cope with and recover from their mental illnesses and addictions. The Committee heard about the enormous challenges that they face and the tremendous barriers that hinder their efforts to recover: their confusion and frustration over how and where to find help; ignorance, lack of compassion, and poor treatment from health care professionals; long wait times for service; and the stigma and discrimination that make so many affected individuals hide their problems and often even avoid seeking help in dealing with them.

1.2.1 Confusion and Frustration

Tom, Paul, and James illustrate the frustration too many people experience in finding the assistance they need:

I wanted to call for help. I had no food, was very cold. I was truly destitute. In calling the local addiction service I got an answering machine repeatedly. I had no phone number to leave. I hung up the phone and cried and cried. After that I became utterly homeless, was in jail and attempted suicide. What if someone was able to answer that phone?
—Tom

I no longer have any hope or expectation that I will recover, nor do I feel that the government will ever provide me with any kind of meaningful treatment to help me overcome this illness.

(...)

So by giving up all hope I never find myself forced deeper into depression by a rejection and the quashing of hope.

—James

It is nearly impossible to get a full picture of the support available and how I can access it. Much of the information is disjointed and difficult for a layperson to understand. —Paul

In short, I gave up all hope in life. I no longer have any hope or expectation that I will recover, nor do I feel that the government will ever provide me with any kind of meaningful treatment to help me overcome this illness.

I live in a single room, alone, where I live out my days. The only reason I haven't killed myself is to spare my parents the pain it would cause.

I have never turned down a treatment, not even experimental drugs which I have tested on a couple occasions. However, without an advocate or a willing psychiatrist, I'm in no condition to face the continual rejection by specialists who hear my story and feel they can't help me. So by giving up all hope I never

find myself forced deeper into depression by a rejection and the quashing of hope. —James

1.2.2 Lack of Knowledge and Compassion

Among others, Deborah, Jennifer, and Rafe told the Committee about the lack of knowledge and compassion that they encountered within the health care professions:

If you are working in the mental health system, you have to care. You have to show people respect and dignity. This is something that I find is still missing. —Deborah Jackman⁵

**Can you imagine if a woman went in to see her doctor with a lump on her breast being told, “Sorry, madam, I do not do lumps, but I can get you in to see a specialist within six months to a year.” Yet, the equivalent of that happens regularly to people who have overcome the stigma attached to mental health and go to their doctor.
— Rafe Mair**

To speak from my personal experience, being on a psychiatric ward was one of the most traumatic experiences of my life.

The things that happen on a psychiatric ward taken in any other context would be seen as devastating. People being locked in tiny rooms they cannot leave, tied to a bed and injected with chemicals against their will are clearly traumatic experiences. Being told that it is all right because they are in a hospital is really a departure from reality. —Jennifer Chambers⁶

Can you imagine if a woman went in to see her doctor with a lump on her breast being told, “Sorry, madam, I do not do lumps, but I can get you in to see a specialist within six months to a year.” Yet, the equivalent of that happens regularly to people who have overcome the stigma attached to mental health and go to their doctor. —Rafe Mair⁷

1.2.3 Lack of Services

Many participants, including Pat, Francesca, Susan, and Raymond, told the Committee that, aside from being confusing and frustrating to access, many times services are simply not existent for those who have a mental illness:

⁵ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁶ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁷ 7 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/19evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The only resources we have in any abundance, yet again, are expensive psychiatrists, occupational therapists, and nurses and social workers who are reduced to delivering pills and needles, effectively keeping discharged patients in chemical straightjackets for the comfort of the mainstream community.

If a client is depressed and upset because his life is so narrowly constricted, his medication is increased. If he is fearful of a landlord or unable to sleep in an overcrowded room, his medication is increased. If poverty leaves him hungry and restless, his medication is increased, and if he has enough remaining life inside his body to be angry, the dosages will ensure that that anger is forgotten. —Pat Capponi⁸

We should not be concerned with what is good for the staff; we should be concerned with how these patients will get better and ultimately end up going back to their lives.

—Francesca Allan

Another huge problem in the hospital is that they are looking for ease of management. Like, it is easier when people are drugged, they are no trouble, and they are just staring at the wall, staring at the TV. That might be a good thing for the staff.

We should not be concerned with what is good for the staff; we should be concerned with how these patients will get better and ultimately end up going back to their lives. —Francesca Allan⁹

Statistics prove that medication alone is not as successful as a combination of both psychotherapy and medication. Other forms of therapy are not available to those of us on fixed income or incomes that do not allow for the sometimes high cost of therapy through psychologists, social workers and alternative therapists.

[...]

I am slowly making my way back to a state of mental health, but will not be able to do so without the assistance of a psychiatrist and a psychologist. Our provincial health plan covers the cost of psychiatric services, but does not cover the cost of psychological services. I must pay for this unassisted by any private

⁸ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁹ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

medical plan. My family is surviving on one income... —Susan Kilbridge-Roper¹⁰

...what people need sometimes is a safe and comfortable place, open at hours they want, accessible to their needs, and feeling, and having a feeling of community and sharing food, talking to one another, laughing together, and helping one another. Unfortunately, here in Ontario, that does not constitute billable hours, so we do not get the kind of financial support that we need, but it is just as valid and just as helpful. —Raymond Cheng¹¹

1.3 WHAT ARE INDIVIDUALS LIVING WITH MENTAL ILLNESS ASKING FOR?

1.3.1 The Social Determinants of Mental Health

People personally affected by mental illness identified for the Committee a number of services they believed necessary for them to cope with and recover from their disorders. Social supports such as employment assistance and adequate housing, education and research, and self-help and peer support are those that were considered most important.

Our provincial health plan covers the cost of psychiatric services, but does not cover the cost of psychological services. I must pay for this unassisted by any private medical plan. My family is surviving on one income...

—Susan Kilbridge-Roper

Witnesses like Diana and Raymond explained that the social determinants of mental health have been largely overlooked despite their importance in preventing and in treating mental illness:

There has been a complete lack of attention to the social determinants of health as they relate to people with mental health or addiction issues.

[...] Good health implies participation, self-determination and good self-esteem. —Diana Capponi¹²

¹⁰ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹¹ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹² 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

...Mental health is integrated with one's physical, social, spiritual and economic well-being. Hope for a future is truly realized if there are genuine expectations that inequities within society will be addressed.

My friends [...] have already eloquently spoken about what it feels like to have a job, a place to call your own, and a social network of friends. I hope you heed our collective call that individual recovery from mental health is impossible when struggling with the consequences of poverty alongside stigma and discrimination. —Raymond Cheng¹³

1.3.2 Employment Assistance

Karen, Joan, and another participant who wished to remain anonymous explained the difficulty often met by people living with mental illness who are trying to find jobs:

...individual recovery from mental health is impossible when struggling with the consequences of poverty alongside stigma and discrimination.
—Raymond Cheng

In my own case, because I had been so open about my illness, it took me a number of years to find decent, secure employment. I felt that people now saw me as a gamble. If I had survived cancer, diabetes or high cholesterol, I'm not sure I would have faced the same challenges. —Karen

People are petrified to go off of their income assistance, because when they stop and think about it, in the real world if they were out working, they would have to make upwards of \$50,000 a year to be able to stay on their medication.

I know of one individual whose medication totals \$1,500 a month, and that in itself is shocking, not that the person is taking that medication at that expense, but the fact that they are caught between the rock and hard place. Yet, at the same time, they want to work, but know that their skills base does not allow them to make the money to be able to support their medication. —Joan Edwards-Karmazyn¹⁴

The way the Ontario Disability Support Program is set up, discriminates against people with mental illness who want to work because if they earn more than \$160 a month ODSP is

People are petrified to go off of their income assistance, because (...) if they were out working, they would have to make upwards of \$50,000 a year to be able to stay on their medication.
—Joan Edwards-Karmazyn

¹³ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07eve.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁴ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

clawed back, guaranteeing that they will always be below the poverty line.
—Anonymous

1.3.3 Safe and Adequate Housing

Katherine and Scott explained that individuals with a mental illness often also face difficulty in finding safe, adequate housing:

Good luck finding adequate housing when they find out you have a mental illness.

—Katherine

Good luck finding adequate housing when they find out you have a mental illness. —Katherine

There are sections of this city, and many others in Canada, filled with boarding homes, and in those boarding homes and group homes, you will find people who have little more in their lives than regular doses of medication. Many of them live with little meaning or purpose because Canadian society fails to recognize they have worth. Some struggle with poverty so grinding and housing so appalling, it would challenge the sanity of even the strongest among us.
—Scott Simmie¹⁵

1.3.4 Peer Support

Many witnesses identified peer support groups as one of the most important services needed on the road to recovery from mental illness. Susan, Joan, Jean-Pierre, an anonymous contributor, and Roy told the Committee about the importance of peer support:

(...) I learned more from my peers than I did in the previous 12 years dealing with what I call the “formal mental health system”.

I learned by listening to how others kept themselves well and what they did to maintain their mental health. I tried some of their methods and some of them worked. (...) I have not taken any medication since then nor have I received any formal mental health treatment since the year 2000.

—Jean-Pierre Galipeault

The value of self-help and support groups in recovery has been very well documented. My own experience as both a member and a leader of one such group has given me an intimate knowledge of the benefits that can be derived from sharing the joys and sorrows that we as people with common problems face on a daily basis. —Susan Kilbridge-Roper¹⁶

Why self-help? People involved with their peers within self-help groups take on a proactive approach towards managing their problems and finding solutions.

¹⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁶ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The focus is on wellness and not illness, on ability and not disability, on becoming at ease with one's limitations and not remaining diseased within one's limitations, on focusing on the beginning of the recovery process and not on remaining stagnant within one's misery. It is about gaining the energy to have choice once again and setting about to plant the seeds of choice to enable the consumer-survivor once more to feel alive. —Joan Edwards-Karmazyn¹⁷

I received my diagnosis quite a few years ago and it is fair to say that many Canadians with a mental illness treat that illness with medication. I spent almost 12 years trying to find the right medication.

Perhaps I am a slow learner, but when I found a self-help group, the light bulb went on.

[...] I learned more from my peers than I did in the previous 12 years dealing with what I call the "formal mental health system".

I learned by listening to how others kept themselves well and what they did to maintain their mental health. I tried some of their methods and some of them worked. The group experience led me to develop a personal recovery plan and in 1996, I went off my psychiatric medication. I am not an advocate of this generally, but I decided on this course because of concerns about long-term side effects. I have not taken any medication since then nor have I received any formal mental health treatment since the year 2000. —Jean-Pierre Galipeault¹⁸

We need some programs available for people to learn skills/tools to help them cope better with people, relationships, stress, anger, sadness etc. Support Groups should always be available to attend, even just having a drop in-group or something so people come when they want.

It really does help to be able to talk to people who understand what you're going through and won't judge you. They may have some suggestions that worked for them in similar situations in the past that you may want to try. It's imperative to have a safe place to be able to talk openly about how you feel. —Anonymous

¹⁷ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁸ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

I have been living with a mental illness for almost 30 years.

[...]

I first received psychiatric treatment in the 1970s [...] [I]n 1979, I was hospitalized for the first time with a “nervous breakdown,” or what we recognize today as depression. The experience, to say the least, was horrible. This was a time when it was very common for people with a mental illness to be extremely overmedicated.

[...]

I somehow made it through the 1980s. I lost my business, my marriage broke up, and I became a person that I really did not like, but I refused to admit that there was something wrong [...]

Then came the 1990s. I became very ill throughout most of that decade. I attempted suicide twice and came very close on numerous other occasions. I had many hospitalizations and was on many different medications over the years and even went through a series of shock treatments [...]

In hospital, I was treated with respect and kindness, but I could see how overworked everyone was. At this time, I educated myself on depression and was willing to try anything that was suggested in order to get well. Nothing seemed to work [...]

I learned through volunteer opportunities that I had a natural ability to talk with and listen to other mental health consumers, and we all seemed to benefit from that [...]

This was a dream that I never believed could happen. As I sit here before you today, I am living proof that dreams can come true. In 2001, I was offered a job at the Consumer Initiative Centre, a program of the Self-Help Connection, an organization built on the power of peer support. I was hired as a peer support worker. —Roy Muise¹⁹

1.4 STIGMA AND DISCRIMINATION

The stories of stigma and discrimination recounted throughout this chapter have only scratched the surface in revealing the attitudes and unjust treatment experienced daily by those living with mental illness.

Many contributors pointed to instances in which they had personally experienced stigma and discrimination in every aspect of their lives solely because they had been diagnosed with a mental illness or lived with an addiction.

¹⁹ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

1.4.1 Stigma and Discrimination in Housing

Linda's and Phillip's stories illustrate the difficulties individuals with a mental illness have in finding safe and adequate housing:

No one really knows what it is like until they experience living in a dark, damp room with no windows, no refrigeration, no heat and no rights. At the time I felt fortunate just to have a roof over my head and a bed to sleep in. I paid \$550 a month for this, a cockroach-, a mouse-infested room with the bed springs that scratched my body.

The bed springs made it impossible for me to sleep so I changed mattresses only to find the new mattress loaded with bed bugs. As horrible as this picture may seem, it was actually worse than I could describe. I was suffering from severe depression and finding myself in and out of hospital repeatedly. I lived in places like this for a good part of my life.

[...]

When I first saw my one-bedroom apartment, I could not believe it was mine. I did not think that I deserved such a beautiful place. I actually thought it might have been a mistake and it would be taken away from me. I had windows, they opened and I could see out; oh, the light, the sun. I could smell the grass and hear the birds. I had my own bedroom, my own washroom. I have a full kitchen with a stove and a refrigerator. Now I am able to cook my own meals and I can entertain with pride.

[...]

My life has completely changed since I moved into my own apartment. It is not just an apartment. It is my home. I am now a productive member of society.
—Linda Chamberlain²⁰

My life has completely changed since I moved into my own apartment. It is not just an apartment. It is my home. I am now a productive member of society.

— Linda Chamberlain

The homeless and mentally ill also have a right to live wherever they want, like anybody else. Nobody has a right to prevent us from living in their neighbourhood.

— Phillip Dufresne

In the process of advocating for more supportive housing, often we must fight NIMBYism, Not In My Backyard; the stigma of mental illness; and zoning bylaws that discriminate against supportive housing.

The homeless and mentally ill also have a right to live wherever they want, like anybody else. Nobody has a right to prevent us from living in their

²⁰ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

neighbourhood. This is blatant discrimination and a flagrant violation of human rights.

How would anybody in this room like it if somebody came up to you and said, “We do not want you living in our neighbourhood”? It does not matter why they say it to you; it is wrong. People are not allowed to prevent Blacks, gays or Jews from living in their neighbourhood because it is considered a hate crime and they should not be allowed to do this to the homeless and mentally ill either.

Nobody is criticizing us because of anything we have done wrong. They are criticizing us out of fear and ignorance. —Phillip Dufresne²¹

1.4.2 Stigma and Discrimination in the Health Care Professions

Lisa, Sheila, Anita and Jeannie describe stigma and discrimination of another kind — from health care professionals themselves. The Committee has always found it difficult to understand how some professionals to whom vulnerable people turn for help could so often treat them in such a shabby way:

*I felt condescended to, and belittled by many of the doctors I came across in the mental health system.
—Lisa*

The health care profession is not very comfortable with any one of its own having a mental disorder.

—Sheila Hayes Wallace

In our community, the only way to get prompt psychiatric care is to attempt suicide or commit a crime. That, in itself, is a crime.

—Jeannie

The health care profession is not very comfortable with any one of its own having a mental disorder. It is kind of a “not in my back yard” attitude. Once labelled as damaged, that worker should go “somewhere else,” not remain in this workplace. —Sheila Hayes Wallace²²

I have waited in an Emergency Room for as long as 6 hours, in a suicidal state, while others with physical ailments have proceeded ahead of me.

The person at the desk who filled out the necessary paper work was informed of my condition. Yet in spite of this I was made to wait as another incoming patient had physical signs of distress, blood, broken bone.

Another thing is when one finally gets in to talk to someone, it's usually the psychiatrist in training, he asks many questions then he gets in touch with the

²¹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²² 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Dr. on call, then the Psychiatrist on call comes to see you and you are asked the same questions all over again. For a person with extreme anxiety this is very frustrating and is enough to put you over the edge at which time you now are treated as a violent patient. —Anita

In our community, the only way to get prompt psychiatric care is to attempt suicide or commit a crime. That, in itself, is a crime. —Jeannie

1.4.3 Stigma and Discrimination Upon Return to Work

Another form of discrimination faced by people diagnosed with a mental illness — said by many who spoke to the Committee to be prevalent in the insurance industry — applies to those seeking to enter or re-enter the workforce as part of their efforts at recovery.

**(A bank...) asked me to fill out a form, and of course one of the questions was, "Have you ever had a mental illness?" And once you tick "yes" in that box, you will be denied insurance at Canadian banks.
—Scott Simmie**

Many witnesses, like Scott and Darrell, told the Committee of the difficulty they experienced in trying to obtain life, disability, or medical insurance and in filing provincial workers' compensation claims:

In my own instance, I was off on disability, finally getting back to work and was going to get an RRSP loan. I went to the bank, a bank I had dealt with for years, and they said they would be happy to give me a loan. I told them I would like to get some insurance on the loan, because I was just returning to work and was not sure how long I would be there. They asked me to fill out a form, and of course one of the questions was, "Have you ever had a mental illness?" And once you tick "yes" in that box, you will be denied insurance at Canadian banks. —Scott Simmie²³

...you are not allowed to overcome your illness or any depression that you might have had. If you have indeed seen a psychologist or a psychiatrist at one point in your life, that will be brought out in order to diminish the claim or the extent of the claim when establishing PTSD or chronic pain syndrome, as in my case.

This abuse is so extreme, and so heavy, that I have come to the conclusion that there is no way that it could be dealt with when it is done on purpose without

²³ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

opening up the human rights portion of the Charter. We have no powers as individuals to access our Charter rights. We do not. —Darrell Powell²⁴

1.4.4 Stigma and Discrimination in Society

Perhaps the most damaging effect attributed by witnesses to stigma and discrimination was that originating in the belittling, denigrating attitudes toward mental illness and those who suffer it that seem to pervade all levels of society. Scott, Francesca, Ruth, Diana, Patricia, Kim and an anonymous contributor are but a small sample of the individuals who shared with the Committee the injuries they have suffered from these attitudes:

When I first began researching mental health in 1998, I went to the largest psychiatric hospital in Toronto, and on the grounds of that hospital there was a sign. The sign was supposed to say “Dogs must be kept on a leash.” Someone had spray-painted out the word “Dogs” and had put in the word “Nuts.” “Nuts must be kept on a leash.” Every time I drove by that hospital for an interview, I checked to see if that sign was there. Patients would have seen it, doctors would have seen it, and the public would have seen it. Eight months after I began my research, someone had finally spray-painted out the offending word.

I was a counsellor, I was a substitute teacher, I was a daycare worker, I worked in a women's shelter, but once they labelled me “mentally ill” I lost all credibility.

—Ruth Johnson

Why do we who suffer with this debilitating disease have to suffer socially as well?

—Kim

Now, imagine a different scenario; picture a similar sign on the grounds of a synagogue. If the word “Dogs” had been replaced by “Jews,” people would have been outraged. The police would likely have been called, the act would have been described, accurately, as a hate crime, and rest assured, the sign would have been gone the very next day. Yet, the sign at the hospital remained unaltered for all that time, and who knows how long it had been there before I first noticed it. —Scott Simmie²⁵

I cannot tell you how profound an impact a psychiatric label makes on your life. I mean, I lost my job and I lost my means for getting another job because I had been in the hospital. —Francesca Allan²⁶

²⁴ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁶ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

I was a counsellor, I was a substitute teacher, I was a daycare worker, I worked in a women's shelter, but once they labelled me "mentally ill" I lost all credibility. —Ruth Johnson²⁷

Whenever someone comes out as having a mental health issue, whether it is an employer, a small business operator or a person on the street, immediately, there are no expectations of those people, and I am not exaggerating when I say that. Actually, there is a fear, quite frankly, that you might be violent. That is the number one fear, and that is perpetuated. —Diana Capponi²⁸

I have volunteered for almost 20 years now and the last three years I have been a member of the Board of Trustees of CAMH. Notwithstanding that long-term achievement and 33 years of a teaching career, when I meet people and I say that I am a recovering addict, there is a drop in credibility. It is visible. It is fine to be a trustee. It is fine to be a retired teacher. It is fine to be a grandmother, but if I say that I am a recovering addict, there is that drop in credibility. —Patricia Commins²⁹

Broken. Lonely. Hopeless. Ashamed. Rejected. Isolated. Afraid. Unsupported. Lost. Anxious. Disbelieved. Overwhelmed. Embarrassed. Dark. Pained. Desperate. Fading.

I'm a 31-year-old Canadian woman who has been fighting the disease of Depression since my late teenage years. The words above are words that come to my mind when I think of what it's like to live as a Canadian in Canada with Mental Illness.

It's pretty sad when you sit around wishing you had any (literally ANY) other disease other than a Mental Illness. There is so much shame, stigma and disbelief that accompany a diagnosis of a mental illness. It's the constant justification that you're actually sick. Why do we who suffer with this debilitating disease have to suffer socially as well? —Kim

²⁷ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁸ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

I shouldn't feel shame or fear or failure because I have a mental disease (Bipolar disorder). I should be able to get help and support as any other person with a disorder or disease. I should not need to try to educate people who do not want to learn about the illness but still have the power to make decisions about my life. —Anonymous

1.4.5 Suggestions for Ending Stigma and Discrimination

Those who told the Committee about their experiences with stigma and discrimination also provided ideas for eliminating such attitudes and making society more accepting of those living with mental illness.

1.4.5.1 Education and Awareness

Almost unanimously, participants agreed on the need for education about mental illness and those affected by it. Patricia and an anonymous participant talked about the need for education and how it would help to alleviate stigma and discrimination:

Only by changing our perception, removing the social stigma and understanding more about mental illness can we as a society begin to improve the treatment and care provided to the people who suffer from a mental disorder.
— Anonymous

Only by changing our perception, removing the social stigma and understanding more about mental illness can we as a society begin to improve the treatment and care provided to the people who suffer from a mental disorder.

Changing our perception means opening the door of hope for thousands of Canadians. It will mean giving the issue a higher visibility among our elected officials and a greater priority when developing our policy initiatives. Fear of mental illness reduces resources and assistance to mental illness.
—Anonymous

The benefits and rewards of recovery can be identified by gathering information directly from recovering clients who are willing to disclose. This is difficult. There are not so many people in Canada who are willing to do this but there are some. Let us find them.

Public figures and private citizens, people from all walks of life might be motivated to speak up and share their insights, or to provide them in written form. Many people regain their lives and go on to be fully participating members of society. How did they do it? What helped them the most? What do they have to offer? —Patricia Commins³⁰

³⁰ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

1.4.5.2 *Stigma and Discrimination in the Media*

Roman and an anonymous contributor were among the participants who suggested that the media would be the most effective means of spreading insightful information about mental illness:

Film and television have used mental illness to add drama to their productions by suggesting the character may be, or is, suffering from an illness, regardless of whether or not the character's behaviour could be attributed to other causes, either emotional or physical. The industry must be alerted to the damage these actions are inflicting on the mentally ill, and the harm they are doing in stigmatizing persons with a mental illness. —Roman Marshall³¹

More media coverage on the reality of mental illness, as opposed to the sensationalism and stigmatism of it, would be beneficial. People need to be taught that people with mental illness are not homicidal maniacs, as depicted on TV, but are friends, neighbours, professionals, etc. —Anonymous

1.4.5.3 *Recognition of the Seriousness of Mental Illness*

Many participants also emphasized the importance of treating mental and physical illnesses with equal seriousness both within the medical community and in society more generally. Frank, Lisa, and Sheila, together with others quoted previously in this chapter, explained that mental illness is often treated differently and with much less urgency and importance than physical illness:

Mental illness is a physical illness, not some disease that enters the minds of the weak or characterless. Like cancer, it can happen to anyone.

Let's start treating "mental" illness as what they are. Devastating diseases.

—Lisa

I have had occasion to sit in the Regina General Hospital emergency room with friends from my group. We have gone home in despair. Unfortunately we are not a high priority, and I do not know why. Maybe if we had blood coming out of the side of our heads we would become a priority.

I will be graphic and blunt about this: We are not important. We do not seem to be important to the health professionals. I do not want to sit in another emergency room because a friend has said, "I cannot keep on living; I need help." I take them there and we are told to sit down.

There is a little board that says the next non-priority patient will be seen in three to four hours. I do not want to see that again. This person needs a room, needs safety. They may not need medication or anything like that, but

³¹ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

they need safety. They want to know that somebody cares, and an open emergency waiting room is not the place for them to be.

We are looking and asking for respect and dignity. —Frank Dyck³²

Start treating mental illness as a biological illness the same as any physical disease. When we say that someone is sick we don't say "physically ill" so why do we say "mentally ill"? Mental illness is a physical illness, not some disease that enters the minds of the weak or characterless. Like cancer, it can happen to anyone.

Let's start treating "mental" illnesses as what they are. Devastating diseases. —Lisa

How many corporations and businesses resisted putting ramps and elevators in place? Well, the business community did not collapse and now it is possible for people in wheelchairs and those who are people who are hearing and visually impaired to work.

Well, you know what? Now we need the equivalent for people who have mental needs. We need our own "ramps," for want of a better word. —Sheila Hayes Wallace³³

1.5 CONCLUSION

Throughout the consultation process, the Committee heard time and time again about the hardships faced by people living with mental illness and addiction, as well as about the resilience they demonstrate. Amidst the expressions of frustration, loneliness, and abuse, there were compelling stories of courage, hope and triumph over adversity.

When we do speak, please do not avoid us. What we have is not contagious.
— **Sheila Hayes Wallace**

³² 2 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³³ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

People with personal experience with mental illness or addiction have been full, contributing partners to this first-of-its-kind study. Without their courage to step forward and share their stories with the Committee, this report would not have been possible. The Committee is most grateful for their willingness to share their intense and often painful personal experiences in an effort to improve the mental health, mental illness and addiction services in Canada for themselves and for others.

When we do speak, please do not avoid us. What we have is not contagious.
—Sheila Hayes Wallace³⁴

³⁴ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

2.1 INTRODUCTION

*The worst is not being able to help because you aren't part of the solution.
—Darlene*

Of the many submissions received by the Standing Senate Committee on Social Affairs, Science and Technology, a great number came from family members who provide unpaid, non-professional care to those living with mental illness and addiction. Like Darlene, many caregivers feel excluded, ignored by the mental health, mental illness and addiction system in Canada. Ironically, it is these same family members who often provide most of the care and support to people living with mental illness.

Families spoke to the Committee of their multiple frustrations: with the mental health system; with the effects that caring for a mentally ill individual have on families; and with securing what they need in order to provide the best possible care for their loved ones. Committee members were struck not only by the impact that mental illness can have on the life and health of caregivers, but also by the fact that the enormous efforts of caregivers often go unrecognized and unappreciated by professionals and others in the mental health system.

2.2 EXPERIENCES WITH MENTAL HEALTH AND ADDICTION SERVICES

Mary, Donna, Doris, Bonita, and Carolyn shared with the Committee the difficulties involved in struggling on behalf of a family member exposed to poor and delayed treatment by the mental health system; they told stories of their loved ones seeking help, only to be turned away or brushed off:

In the end, just to sum up, the tragedy does not lie with the disability; that is not the tragedy. The tragedy is in the way society treats the child and the family that is dealing with the disability.

—Donna Huffman

When our son was 24, he killed himself. Just maybe, if he had gotten proper care and a psychiatrist who was truly interested in what was bothering him back then, maybe he would be with us today. —Mary

Unfortunately, access to care is a daily struggle. All the services you get in terms of your child with a psychiatric illness are as a result of hard-fought, hard-won battles.

[...]

In the end, just to sum up, the tragedy does not lie with the disability; that is not the tragedy. The tragedy is in the way society treats the child and the family that is dealing with the disability.

We can handle Alex. So far, we have been able to do so with the limited amount of support that we have been able to get, and we are very appreciative for that limited support. What we cannot do is constantly fight to get every single service. —Donna Huffman³⁵

In September 1984 I received a phone call from my son's landlady in Toronto advising me he was in a hospital psych ward after attempting to fly out of the window of his upstairs apartment. I was convinced then that it was the worst day of my life but of course it was not. It was the beginning of a catastrophic rollercoaster ride, culminating nine years later with him being judged not guilty of a second degree murder charge on the grounds that he suffered from a mental disorder.

When he was informed of what he had done, he spent three days throwing himself against the walls of his jail cell in an agony of intense remorse. During that time and during his four-and-a-half years at the Forensic Psychiatric Institute in Port Coquitlam he never received any psychological counselling other than a few group counselling sessions initiated by the institute's very kindly pastor. —Doris Ray³⁶

I have taken my son into the emergency room in a manic state and, trust me; it is an awful thing to do. I mean, he is walking around telling people they are witches and grabbing the magazines out of their hands and scaring them and I am sitting there thinking oh, my God, what is he going to do.

I had to argue with the doctor about his condition. They tried to tell me that he is on drugs or he is this or that.

I said: "Look, I know what he is. I know he is mentally ill. He has records, can't you get them?" No, it was just too much trouble. You have to get into a major argument with these people. So something needs to change there, that is for sure. —Bonita Allen³⁷

³⁵ 1 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁶ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁷ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

I speak as the mother of a young woman who died after eight years adrift with severe anorexia-bulimia in a medical system that basically ignored this most deadly of the mental illnesses.

[...]

Within the mainstream of the medical system, Danielle often faced hostility from her medical treatment providers. She was treated as if this was some kind of wilful teenage thing, some kind of hissy fit that she was having. Not true. [...] Every bite, every step was a genuine struggle for her.

In addition, she did not receive care for anything not deemed part of the problem. Her bones deteriorated to the point where she was off the chart, but she was not eligible for the bone medicines because they only went to 65-year-olds.

[...] She did not receive use of the air bed, although they brought one into her room in the hospital in the hour before she died to relieve the pain of the bones and the muscles which had all withered so that she had no range of motion.

[...]

One sarcastic nurse said to us, “Well, what exactly do you expect of us?” and I said, “I would like to find a cognitive behavioural therapist for Danielle and a psychiatrist who could work different medications until he found the right one for her severe suicidal impulses five days every month.” The nurse looked at me and said, “You are being absolutely unrealistic.”

[...]

Danielle was turned away three times at emergency rooms when she went there scared that she might act on these suicidal impulses, because she wanted to live. It was not an attention-getting thing. They laughed at her plans. [...] One time, five days later, she had a good plan and she overdosed. I found her.

When she was in Toronto for two years waiting for her turn that never came up, at our expense in a rented room, she would go to the hospital emergency and stay between the double doors, because there she could wait safely until the impulse passed. She knew it would pass, but she had to be safe until it did.
—Carolyn Mayeur³⁸

I speak as the mother of a young woman who died after eight years adrift with severe anorexia-bulimia in a medical system that basically ignored this most deadly of the mental illnesses.

—Carolyn Mayeur

³⁸ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Carol's was one of the few hopeful messages we heard:

My experience with mental health services is a result of my older son Peter being diagnosed with schizophrenia when he was 19. Peter is now 45 and I count him as a sort of success story, given the seriousness of his condition.

Since those days, Peter has been put on more modern medication. He has gained a university degree in Mathematics (it took 20 years); he works as a teaching assistant in [a university] math department [...]; he takes benefit from the Centre for the Disabled at that University; he continues his education with law courses; he works as a security guard sometimes; he volunteers for many causes; he lives with a woman who also has schizophrenia; and he counsels and advises other people he knows who have this condition or some similar mental problem. —Carol

2.2.1 Lack of Information

Heather and Donna communicated to the Committee their dissatisfaction with the confusion and lack of information about where to turn for help when a loved one needs it. Many family caregivers explained that the greatest difference between a mental illness and a physical illness is that, for the former, it is so much more difficult to find information and assistance:

Trying to get help is a frustrating, lonely journey. Most people make many, many calls in an effort to get help. When you finally find something that looks hopeful, you get on a ten month waiting list... it is like showing up in emergency with a broken bone and being told, yes, it is really broken, so try and do what you can with it and we will see you in ten months.
—Heather Dowling

When your child breaks an arm or a leg, you know where to go. You know that when you go there, someone will help you. You go to the emergency department and the nurse sees you, the doctor comes, you have an x-ray, and either you are given a cast, or worst luck, you need surgery, but you get help.

[...] If you have an eating disorder, it is not like that. You do not know where to go. Your parents do not know where to go for help. Lots of doctors and nurses do not know what to do for you. Many of them blame you for being sick. But you are sick, really sick.

Trying to get help is a frustrating, lonely journey. Most people make many, many calls in an effort to get help. When you finally find something that looks hopeful, you get on a ten month waiting list... it is like showing up in emergency with a broken bone and being told, yes, it is really broken, so try and do what you can with it and we will see you in ten months.

[...] That seems a ludicrous example, no one would ever do that, nor should they. However, this is what happens with mental illness all the time, and somehow it is acceptable.

At age 11, my daughter's treatment and ours as a family would have been very different if she had cancer rather than an eating disorder. [...] The experience of having a child with a mental illness has all of the fear, doubt, searching for answers, trying to cope, stress, and emotional trauma as having a very physically ill child, without any of the supports that a serious physical illness receives.

(...) I often wish my son had been born blind instead, because people recognize that fact. They would take one look at my son and say, "Okay, we know what it is, we know what the problem is, we know the services that he needs," and it would be that, and I would not have to spend so much time advocating and begging for help.

— Donna Huffman

You feel very much alone, and left alone. —Heather Dowling³⁹

I just know myself — and this sounds horrible — but I often wish my son had been born blind instead, because people recognize that fact. They would take one look at my son and say, "Okay, we know what it is, we know what the problem is, we know the services that he needs," and it would be that, and I would not have to spend so much time advocating and begging for help.
—Donna Huffman⁴⁰

2.3 THE IMPACT ON FAMILIES

Family caregivers shared with the Committee numerous stories of the heavy toll on the family imposed by caring for a loved one living with mental illness or addiction, in particular the physical and emotional effects of attending to a relative living with mental illness and the lack of recognition and support for what they do.

When you face the reality that there is basically no treatment that you can find for your child, it just becomes totally unbearable.

— Phyllis Grant-Parker

2.3.1 Physical and Emotional Effects

Carolyn, Joyce, Sheila, Lembi, and Phyllis described some of the physical and emotional effects experienced by family caregivers:

Actually, all three of us in our family have developed chronic illnesses because of the eight years of stress living with somebody who at the end of her life looked like she had been in a concentration camp, and the incredible, non-productive

³⁹ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁰ 1 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

stress of trying to access medical care and being told that we were out of line.
—Carolyn Mayeur⁴¹

As a young person, that is what my daughter said. Why would she bother taking her drugs, if that is all they could offer her? It is a life on medication, with no friends, living on social assistance, no future. What was the point of living? I had to agree with her. I always thought that if it did end up that she did kill herself, I could forgive her, because she would be at peace.
—Jan House⁴²

It is terrible to say, but if my daughter killed herself, I would understand. My daughter has said to me, “I do not know what there is for me when I am hearing these voices and I cannot do this and I cannot do that. Why am I here? I would be better off dead.” We have had intellectual conversations at times where she has had insight and can be quite academic about it, and it is very hard to come up with a reason to live. —Sheila Morrison⁴³

...my husband must re-qualify [for the tax credit] each year. I cannot tell you how stressful that is for him. He has to go to the doctor and ensure that the form is filled out correctly so that there will not be any question about it. This is a hugely stressful annual event. It is stressful for him and, talking about contagion, it is stressful for me. It is as though I take on that kind of stress too, because over the year, there is so much stress in coping with his stress that I cannot draw the line as to where his problem ends and mine begins. His problem is eventually my problem. —Lembi Buchanan⁴⁴

When you watch the impact on your child of a psychotic break and you learn that he or she has a serious mental illness, one that they are going to have to learn to manage for the rest of their lives, it is devastating as a parent, absolutely devastating. When you face the reality that there is basically no

⁴¹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴² 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴³ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁴ 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

treatment that you can find for your child, it just becomes totally unbearable.
—Phyllis Grant-Parker⁴⁵

By contrast, Mark spoke about the positive impact that finding effective services for a loved one can have on a family:

After the last 15 years, my son Kenny, who suffers from severe obsessive-compulsive disorder, now fits into the community after years of family disruption, in and out of hospitals, from one psychiatrist to another, and searching in vain for direction. Because of his compulsive disorder, we are constantly at odds with no cooperation from Kenny. He was living on the streets, with the constant anguish and panic of not knowing where he was; was he safe? At times he would show up in my studio, a street person, my son.

In our desperate search, we finally were able to connect my son into the system providing mental health services of supportive housing. [...] No words can express the feelings and relief a parent has to have their son or daughter function normally and enjoy life connected to community and especially family. We take comfort in knowing that when we pass on, our child will always have a safe, secure, affordable home. —Mark Shapiro⁴⁶

2.3.2 Lack of Recognition and Support for Caregivers

Even though family caregivers spend endless hours searching tirelessly for services and treatments and advocating on behalf of their loved ones, their efforts are often unappreciated or ignored. Joyce, Betty, Mike and two anonymous contributors shared their frustration with the lack of recognition and support for family caregivers:

I will say this much: If families are not at the centre of developing services for families, they will not work. We are pretty tired of providing the services, doing the work and being ignored.

— Betty Miller

Many people in the mental health field don't appreciate the value that family members can be in the recovery process.

— Mike

...as a caregiver, you are in jail as well, because you are afraid to go anywhere for fear that you are going to miss a call — and you do not have the trust that you need to have in the system. Very often, we have felt very hopeless, very abandoned and ignored. I think that really does need to change. —Joyce Taylor⁴⁷

⁴⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁶ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁷ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Please, as we shift our paradigm to put clients truly in the centre, remember who has been providing the bulk of mental health care and addiction care. We have, we the families and the friends, to the tune of billions of hours of “informal” care each year, and many billions of dollars saved in the system. Just take this as meaning that families are unsupported, unpaid, and ignored.

[...]

Ask families what they need and they will tell you. Ask us to help develop a service delivery system. We will. We know the system and we know what works and what does not. We have great ideas.

I will say this much: If families are not at the centre of developing services for families, they will not work. We are pretty tired of providing the services, doing the work and being ignored. —Betty Miller⁴⁸

Many people in the mental health field don't appreciate the value that family members can be in the recovery process. —Mike

Many family members are the sole support services of the mentally ill while trying to provide support to other aging family members and working full-time jobs. The support systems to assist family members are non-existent. Special efforts must be made to reach family members of the mentally ill. —Anonymous

Families play a vital role in the recovery of a consumer. A majority of families live with the consumer 24/7 and so have a unique knowledge of the family member who has the mental health problem. Families provide housing, social, financial support, help in navigating the system etc., and in essence are the first line of support.

They have a unique role in the system — a support to the consumer and at the same time because of their knowledge can work with professionals. This role must be recognized and families integrated not only at the support level but in the policy and implementation levels as well. —Anonymous

⁴⁸ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

2.4 WHAT ARE FAMILY CAREGIVERS ASKING FOR?

Because families often provide a great amount of unpaid and unrecognized care and support, the Committee believes it is essential to listen carefully to their suggestions. Family members told the Committee of their need for a variety of things: better information and education; income support; peer support; respite; access to their family member's care plan and to be included respectfully by physicians and others in discussions of how and by whom that plan will be implemented.

2.4.1 Information and Education

Darlene and an anonymous contributor illustrated the need for more information and education about what their loved one is experiencing and how to help him or her:

When 1 in 100 people has schizophrenia, is it too much to ask to have us all know what it is?
—Darlene

My son was diagnosed with schizophrenia in 1997. He was sent home after only 3 days in hospital and I had no idea where to begin. No information was provided by the hospital; no follow-up phone call or meetings — merely the advice that our local MB Schizophrenia Society had material for me to read.
— Anonymous

My son was diagnosed with schizophrenia in 1997. He was sent home after only 3 days in hospital and I had no idea where to begin. No information was provided by the hospital; no follow-up phone call or meetings — merely the advice that our local MB Schizophrenia Society had material for me to read.
—Anonymous

2.4.2 Income Support

Joan, Phyllis, Norrah and an anonymous contributor shared stories of the financial hardship that is often associated with caring for a relative living with mental illness to whom income supports are not available:

We need to take into consideration the financial burden mental illness brings to families. Disability pensions for the mentally ill are ridiculously low and most families dig into their pockets to provide for basic needs such as new shoes, dental care, health care items and spending money. —Joan Nazi⁴⁹

...while we were very fortunate as a family to get access to this kind of support, it was at a tremendous family cost. It was a five hour drive from Ottawa for

⁴⁹ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

us to see our son. The emotional impact of having him ill that far away was tremendous.

Over the 14 months we drove 49,000 kilometres, lost 50 per cent of our family income, closed a family business, and had \$29,000 worth of out-of-pocket expenses. —Phyllis Grant-Parker⁵⁰

Most of the families I know in this province are suffering beyond what you can conceive of. They are selling their homes, if they have them to sell.

I will speak of my own situation. I have nothing. I will remain in poverty for the rest of my life. [...] I will never own a home, a decent car. I may never even be able to hold down a decent job because of my son's disability. —Norrah Whitney⁵¹

I have a child with autism/ADHD and several medical diagnoses. The simple fact is that if he needs surgery to save him, I can get it in 6 hrs or less.

I have no access to any treatment to help him be a productive member of society unless I fund all treatment myself. However, if I just choose to put him on drugs and let him sit in the corner, the province will willingly provide. —Anonymous

We need to take into consideration the financial burden mental illness brings to families. Disability pensions for the mentally ill are ridiculously low and most families dig into their pockets to provide for basic needs such as new shoes, dental care, health care items and spending money.

— Joan Nazif

2.4.3 Peer Support

George described how important peer support is to family caregivers to share fears and frustrations and to learn coping skills from those with similar experiences:

We try to convey to them that they are not alone on this journey; they have the love and support of all at the meeting to help them through their grief. I have seen people come to a meeting for the first time so devastated that they could not speak, and months later, I have seen the same people laugh for the first time without fear of guilt and shame. —George Tomie⁵²

⁵⁰ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵¹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵² 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

2.4.4 Respite

Betty and Annette discussed the importance of breaks, of respite care for family caregivers. Many contributors told the Committee how difficult it is to find trustworthy and knowledgeable caregivers whom they can comfortably leave in charge of their loved ones:

Families are tired. We need help. We are getting old and we are afraid that our loved ones will be left to fend for themselves on the streets; and those streets exist in both rural and urban communities.

— **Betty Miller**

Families are tired. We need help. We are getting old and we are afraid that our loved ones will be left to fend for themselves on the streets; and those streets exist in both rural and urban communities.

Families need respite care; they need to be shown that not being able to care for someone isn't the same as not caring for someone; they need to feel that there is somewhere for them to go when they simply can't cope anymore.

— **Annette**

Families have legitimate fears and distinct needs of our own. [...] Maybe all we needed was an hour or so of someone helping us figure out our options. Understand that we are a little fatigued, we need a break. Maybe someone can take over for us for a while, give us some respite. —Betty Miller⁵³

Families need respite care; they need to be shown that not being able to care for someone isn't the same as not caring for someone; they need to feel that there is somewhere for them to go when they simply can't cope anymore.
—Annette

2.4.5 Providing and Accessing Personal Health Information

A great number of respondents stressed that access to information about their loved one's care and treatment was one aspect, perhaps the most important, of providing the best care possible for a family member suffering from a mental illness and/or addiction.

Any mental illness extracts a terrible toll on family members. Family members require information, education, and support. Only when absolutely necessary for the sake of the client should family members be excluded from the treatment process.

— **Ruth Minaker**

Brenda, Ruth, Phyllis, and an anonymous respondent spoke of the helplessness they felt as a result of being denied access to information about the care and treatment of their loved one. To compound their frustration, information pertinent to their loved one's care that they wanted to share with health care professionals was often dismissed or refused. Their exclusion is exacerbated by the application of laws that are intended to protect the rights of

⁵³ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

the individual but, in some cases of mental illness, increase the risk of serious harm to that individual and others:

I have a 25 year old son who has been diagnosed with paranoid schizophrenia. He would go on the medication, then feel he was cured, stop the medication and his symptoms would get worse.

Because of the laws he could not be forced to stay on his medication and would eventually go back into the hospital on a form, in which an advocate would go in and ask him if he wanted to be there and of course he would say no.

He is now 25 years old, the voices in his head have become unstoppable and louder for him. His delusions have become increasingly violent and he has such beliefs that he can live forever if he drinks human blood (because God said, drink my blood) and that if he dies he will rise again. I assure you that I and my family, his probation officer, and his two psychiatrists have no doubt that if our son is not treated medically for his illness that he will eventually kill either himself or someone else.

He self medicates himself with drugs, as is common with this illness, to stop the 20 screaming voices in his head.

As a parent I am unable to help my son who so desperately deserves treatment because HE is the only one who can make this decision. All doors are locked to the people who love him the most. His family. We have to stand by and watch him disappear into someone we don't know and who we all now fear for our lives.

Yes... this is our worst life experience. Dealing with the law taking the rights away so that we cannot help our loved one.

I think if a loved one proves time and time again, and in our case when his doctors say he is a danger to himself and others, and cannot function without help, that a loved one of the mentally ill person should be able to step in and be his voice to make him take his medication and to make sure his medical needs are taken care of.

Currently our son is back in jail for threatening our lives. Do we think he will follow through with these plans? Yes we think so, so do his doctors, so does his probation officer, so do the police. You have to remember that when a paranoid schizophrenic is off his medication he doesn't see family, friends as who they really are but in his delusional mind they are people that are trying to kill him.

My son deserves to be treated for his mental illness. But as the law stands now at this point they will wait for him to carry out his threats, and he will, and then all will suddenly stand up and say wow, why didn't we see this coming.

So my simple answer to what could help make things easier on family members is simply to allow the family to help their loved one get better. Untie our hands and bear our pleas, give us back our loved one.

Is it not enough that they are sick? Do we have to punish them for being sick?

My biggest concern is that as a parent to a young man that we love so much, we cannot help him. That we have to watch him get worse and worse every day. We have to watch him being hurled into a justice system that he has no understanding of what wrong he did. He did what the voices told him to do, he did things out of desperation, he was hungry he needed food, he was scared, he was fighting for his life. Kill or be killed.

We know that when he calls us mom and dad he knows who we are, his parents. But when he refers to us by our first names we know that he thinks of us as his enemies. We have lived with locks on our bedroom doors for a few years now. —Brenda Valcheff

Any mental illness extracts a terrible toll on family members. Family members require information, education, and support. Only when absolutely necessary for the sake of the client should family members be excluded from the treatment process.

[...] Long after the treatment team has delivered its services, in most cases the family will still be involved in the life of the client. —Ruth Minaker⁵⁴

I think it is essential that families be involved because we hold the benchmark of our family member. We know the person before their illness, and this illness can, during the early treatment time, seriously change behaviours. The medical team only sees the sick person.

Hence, we hold the benchmark, because true recovery is really to return a person to him or herself, to come back to who they were as close as possible. Therefore, parents and families need to be welcomed as part of the team... —Phyllis Grant-Parker⁵⁵

I have a son with a mental illness. He is an adult, nearly 40 years old. We have had to take care of him, have had suicide watch a number of times, taken

⁵⁴ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

him to emergency numerous times, made sure he got to appointments, supported him emotionally, physically, financially and yet when it comes to input in his psychiatric care we are not even considered.

Our son can spout off lies to his Dr. and there is no way we can have input because he is an adult. Dr.'s need to talk to families or caretakers to ensure that the information they are getting from the consumer is accurate.
—Anonymous

2.5 CONCLUSION

Family members who provide care and support to relatives living with mental illness and addiction face a two-fold challenge. First, they must suffer with their loved ones through their daily hardships and use their limited personal resources to try to alleviate them. Second, they must contend with a mental health system that often excludes them from involvement in the information-gathering and decision-making processes while simultaneously leaving them to serve as the fail-safe mechanism to provide unlimited, unpaid care, filling in the cracks that open when any part of the so-called system fails.

Do the people in public office need to lose a child to understand how desperate the situation of mental health is in Canada? Unfortunately it seems the only people who really care about this are those who have experienced it first hand.

— Ginny

Family members who provide care and support to relatives living with mental illness have their own unique perspective on the mental health system and its reform. They have shown the Committee that despite their frustration and fatigue, they will continue to search for assistance for their loved ones and to provide it themselves when they come up empty-handed. The Committee acknowledges the contribution to this study made by these individuals. Their stories are valid; their voices must be heard; their recommendations must be acted upon.

Do the people in public office need to lose a child to understand how desperate the situation of mental health is in Canada? Unfortunately it seems the only people who really care about this are those who have experienced it first hand.
—Ginny



PART II

Overview

CHAPTER 3: VISION AND PRINCIPLES

Given that a model tends to shape our perception of circumstances, it substantially influences how and what services we seek to construct, be they in mental health or in physical health.⁵⁶

After two and a half years of studying the mental health and addiction “system” in Canada, it is still striking to the Committee how many key questions about that system cannot be easily answered. They range from factual matters (e.g., how much is spent annually in each jurisdiction on mental health services and supports?) to fundamental philosophical, medical and scientific issues relating to the nature of mental illnesses.

The Committee has heard many different points of view on the whole range of questions, all argued with passion, integrity and eloquence. The previous two chapters bear witness to the richness of this testimony.

In recent years, much progress has been made in developing new medications and new treatment methods for many mental illnesses. As well, people living with mental illness and their families have increasingly been making their voices heard and have rightly insisted on actively participating in making the decisions that affect them. Still, there is a very long way to go. This is why, in the background reports released in November 2004, the Committee clearly affirmed that maintenance of the status quo with regard to mental health, mental illness and addiction in Canada is not an acceptable option.

In the Committee’s view, what is needed is a genuine system that puts people living with mental illness at its centre, with a clear focus on their ability to recover. This chapter explains what the Committee means by recovery and lays the foundation for what follows in the report.

3.1 INTRODUCTION

3.1.1 The Limitations of this Report With Regard to Substance Use Issues

The Committee believes it is necessary at the outset to acknowledge something that will become quickly evident to the reader of this report. The Committee has not been able to devote as much attention to substance use issues as it intended when it embarked on its study of “mental health, mental illness and addiction.” This report therefore focuses primarily on mental health issues.

There are, of course, many areas of overlap between mental health and substance use issues, not least of which involve people living with both mental health and substance use disorders. It is quite common for people to suffer from both. Research has shown that 30% of people diagnosed with a mental illness will also have a substance use disorder in their lifetime and

⁵⁶ Anonymous participant, second e-consultation.

37% of people with an alcohol use disorder (53% who have a drug use disorder other than alcohol) also live with a mental illness.⁵⁷

The relationship between services for mental illness (such as treatment for depression, anxiety disorders and schizophrenic disorders) and services for substance use disorders (including treatment for problematic alcohol use, withdrawal management services, methadone maintenance for opiate addiction and needle exchange programs) has been the subject of much discussion and debate across Canada. In previous decades, services for the two types of disorder were administered separately; they developed divergent treatment philosophies, used different terminology and constituted different ‘cultures’ that were often in conflict.

The ‘culture clash’ between mental health services and addiction services has created substantial problems for clients, particularly those with concurrent disorders. As a result of conflicting approaches to treatment, clients have often received confusing and inconsistent information and advice. It has been common for them to be excluded from mental health services if they admitted to substance use problems. Similarly, clients were often excluded from addiction treatment programs if they admitted to the use of antidepressant medications.

Because of the importance of substance use issues in general, and of this overlap in particular, the Committee has devoted a Chapter of this report to substance use issues, and has attempted to address areas of common concern at various points throughout the report. Moreover, there is an important recommendation in Chapter 16 that the federal government inject an additional \$50 million per year in concurrent disorder programs.

Despite this, however, the Committee is acutely aware of the limitations of this report with respect to substance use issues. This report only scratches the surface of many substance use issues that deserve a much fuller treatment. There are also many places where the Committee has been unable to examine fully the similarities and differences in approach in the mental health and substance use fields. It would clearly not be appropriate for the Committee to assume that conclusions it has reached after carefully considering the mental health evidence necessarily apply with respect to substance use issues. Some may apply, but the Committee has attempted to avoid any unwarranted assumptions in this regard.

3.1.2 Some questions of “language”

The language used to speak about an issue, and the models employed to understand it, have a significant bearing on the kinds of policy proposals favoured or endorsed subsequently. Nowhere does this ring more true than with respect to mental health, mental illness and addiction.

The language used to speak about an issue, and the models employed to understand it, have a significant bearing on the kinds of policy proposals favoured or endorsed subsequently.

⁵⁷ Skinner, W., O’Grady, C., Bartha, C., and Parker, C. (2004) Concurrent substance use and mental health disorders: An information guide. Toronto: Centre for Addiction and Mental Health.

This report is about mental health, mental illness and addiction. How, then, should this report refer to the people most directly affected by mental illnesses and addictions? As the Committee noted in its interim report, there is no single, easy choice:

Traditionally, individuals with mental illness and addiction being cared for by physicians are called patients. Other health professionals often refer to such individuals as *clients* or service users. The individuals may describe themselves by a number of terms, commonly consumers and survivors. Consumers usually refer to individuals with direct experience of significant mental health problems or mental illnesses who have used the resources available from the mental health system.

In its initial reports, the Committee chose to use the term “people living with mental illness” as its broadest reference. It also used the term “patient/client” where relevant. It is important to clarify further how these various terms will be used throughout this report.

In addition to “people living with mental illness” as a generic term, the Committee will also employ the phrase “people with direct experience of mental illness.”

In addition to “people living with mental illness” as a generic term, the Committee will also employ the phrase “people with direct experience of mental illness.” Other terms will be used as appropriate. The term “patient,” for example, can be used when referring to people who are actually receiving medical treatment. Used as a general term, however, it conveys an impression that is overly medical; the Committee heard repeatedly, and compellingly, that more than medicine is involved when dealing with mental illnesses.

The Committee will use the word “consumer” to refer to people who are using available mental health supports and services. It will not be used, however, to refer to all those living with mental illness.

An anonymous participant in the Committee’s second e-consultation put it this way:

In making your final recommendations, I hope the Senate Committee will acknowledge that mental health care is more than psychiatry and clinic services. Though those things are extremely important, they can only be helpful as part of a broader community support system which adequately addresses the needs of mental health consumers. —Anonymous

For her part, Jocelyn Green, Director of Stella Burry Community Services in St. John’s, pointed to the potentially beneficial impact of a broader approach:

The formal mental health system is still too hierarchal and pathology-based. Yes, obviously, there are severe, legitimate mental illnesses that need treatment and medication, but I think we often fail to factor in the systemic roots of many mental health problems, such as poverty, abuse, discrimination, the lack of child care and affordable housing. I think if a lot of those issues were

addressed, certainly a lot of the people that are coming through our formal systems would not need to be there. —Jocelyn Green⁵⁸

The term “consumer” poses similar difficulties. The Committee will use it to refer to people who are using available mental health supports and services. It will not be used, however, to refer to all those living with mental illness. One reason is that the majority of those with a mental disorder or substance use disorder, as shown in a recent national survey conducted by Statistics Canada,⁵⁹ do not access mental health services or supports. Clearly, calling *all* people living with mental illness “consumers” is inaccurate; the same limitation applies to the term “client.”

The Committee is also sensitive to the fact that the term “consumer” has a variety of meanings and is not liked by many to whom the designation might apply. As one respondent to the Committee’s e-consultation wrote:

I do not like the word “Consumer” — I find that stigmatizing. Other people who have illnesses are not defined in this manner. It gives the impression that because of our illness we overuse services. The word makes me think of a fire consuming that which sustains it. It has a very negative connotation and I think it should be dropped. People with personal experience with mental illness is quite adequate... just like people with personal experience with cancer or any other number of known diseases. —Anonymous

Others pointed to the many commercial overtones of the term. For all these reasons, the Committee believes that it is not the best term to use to refer in the broadest way to all those who are living with mental illnesses. In this report, therefore, the Committee will use the term consumer only to refer to those who are in fact using available mental health supports and services, or when speaking about groups and individuals who refer to themselves as consumers.

3.1.3 The Mental and Physical Dimensions of Illness

People living with mental illness and addiction have faced, and continue to face, stigma and many forms of discrimination that compound the effects of their illnesses. As the Committee previously noted, this systematic discrimination is one explanation for the fact that mental illness, in general, is not often treated with the same degree of seriousness as physical illness.⁶⁰ This situation must be redressed.

People living with mental illness and addiction have faced, and continue to face, stigma and many forms of discrimination that compound the effects of their illnesses.

The Committee senses that there is, in fact, a broad consensus in favour of equity of treatment among Canadians. Most would agree that having providers and others treat mental

⁵⁸ 15 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵⁹ Statistics Canada (2003) Canadian Community Health Survey, Cycle1.2, Mental health and Well-Being.

⁶⁰ See Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1—Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Ch. 3.

illness with the same seriousness as physical illness is part of the fundamental entitlement of people living with mental illness to the same rights and privileges as all other Canadians. Achieving equity of treatment would mark an important step in combating the stigma associated with mental illness and addiction and the discrimination against people living with them.

But it is important to clarify what “treating mental illness like physical illness” really means. There is nothing approaching universal agreement on how mental and physical factors influence the state of our mental health. Indeed, there are many different ways in which social, environmental, psychological, and biological factors are thought to interact in the development of mental disorders, although most people seem to agree that mental illnesses almost always entail some combination of these factors.

However, different emphases placed on the role of these four factors can and do lead to very different approaches to mental health policy. For example, someone who believes that the key to “curing” mental illness is an understanding of the underlying functions of the brain, would be much more likely to support spending scarce research dollars on neurophysiology than on studies of the impact on individuals of the social determinants of mental health.

(...) the Committee believes it is extremely important to stress the significance of what are called the social determinants of health in understanding mental illness and in fostering recovery from it.

In the Committee’s view, it is essential to recognize that in treating mental illness comparably to physical illness it is not necessary to treat them as if they were identical to one another. Mental and physical illness are both like and unlike each other. There are key similarities and key differences, many points of overlap, but also features that are unique to each.

In particular, the Committee believes it is extremely important to stress the significance of what are called the social determinants of health in understanding

What the Committee means, then, by treating mental illness like physical illness is best understood to mean that both types of illness must be treated with equal seriousness, by providers, by all Canadians — and particularly by governments.

mental illness and in fostering recovery from it. The Committee was repeatedly told that factors such as income, access to adequate housing and employment, and participation in a social network of family and friends, play a much greater role in promoting mental health and recovery from mental illness than is the case with physical illness. As well, it is important to see that the direction of causality goes both ways, from the mental (psychological, emotional, etc.) to the physical (neurobiological) as well as from the physical to the mental.

What the Committee means, then, by treating mental illness like physical illness is best understood to mean that both types of illness must be treated with equal seriousness, by providers, by all Canadians — and particularly by governments. People who are living with mental illness and addiction must be accorded respect and consideration equal to those given to people affected by physical illnesses. The Committee has sought to make this one of the guiding principles that underpin this entire report.

3.2 RECOVERY

This report focuses on facilitating the recovery of people living with mental illness and addiction. Widely documented in the field of addictions, the idea of recovery has been applied only relatively recently (over the past decade) to mental illness. The goal of recovery for people living with mental illness has nonetheless gained considerable acceptance in that time.

The Committee believes that recovery must be placed at the centre of mental health reform.

The Committee noted previously that:

Recovery is not the same thing as being cured. For many individuals, it is a way of living a satisfying, hopeful, and productive life even with limitations caused by the illness; for others, recovery means the reduction or complete remission of symptoms related to mental illness.⁶¹

The Committee believes that recovery must be placed at the centre of mental health reform. Studies have shown that even people with the most severe mental illnesses who have been decades under institutional care, can and do recover.⁶² Long-term studies of the impact of serious mental

The Committee is aware that not everyone living with a mental illness will be able to recover, but, (...) believes recovery to be the primary goal around which the mental health delivery system should be organized

illness have demonstrated that a significant number of affected people are able to regain full function.⁶³ Research carried out by the National Empowerment Centre, based on in-depth interviews with people diagnosed with schizophrenia, bipolar or schizoaffective disorders, confirms the capacity for recovery.⁶⁴

Although the term recovery also has a number of drawbacks, the Committee nonetheless believes it is the most appropriate one for all the reasons outlined in this section. The Committee is aware that not everyone living with a mental illness will be able to recover, but,

⁶¹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1—Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada,, Ch. 4, p. 79.

⁶² Harding, C. (1987) The Vermont Longitudinal Study of Persons With Severe Mental Illness, II. *American Journal of Psychiatry*, Vol. 144, pp. 727-735.

⁶³ Moran, M. (2004) Schizophrenia Treatment Should Focus on Recovery, Not Just Symptoms. *Psychiatric News* (American Psychiatric Association), Vol. 39, No. 22. Also Jacobson, N., and Curtis, L. (2000) Recovery as Policy in Mental Health Services: Strategies emerging from the States. *Psychiatric Rehabilitation Journal*, Vol. 23, No. 4.

⁶⁴ Fisher, D., and Ahern, L. (1999) People can recover from mental illness. National Empowerment Centre, http://www.power2u.org/recovery/people_can.html. It is interesting to note in this context the results of World Health Organization studies conducted in 1979 and 1992 that looked at recovery rates from schizophrenia in developing compared to industrialized states. Using matched controls, they found recovery rates in developing countries were twice those of industrialized nations. Some commentators have speculated that the more social approach of the developing countries worked to keep people connected to their communities and assisted in their recovery.

as explained below, it believes recovery to be the primary goal around which the mental health delivery system should be organized.⁶⁵

Advocacy groups have been central in promoting the focus on recovery. In this regard, a participant in the Committee's e-consultations commented:

Surprisingly when considering the history of psychiatric treatment recovery can be seen as a radical concept. The demand to see the human potential of consumers and the expectation that help will lead to recovery was spawned by the consumer and family movement. —Anonymous

Kim Baldwin, Director of Mental Health and Addictions Services for the St. John's region, also noted that:

*"Recovery" is a term we have used in the addictions field for a long time and have been getting to know it in terms of mental health as well. It is a concentration on wellness as opposed to focusing on the illness.*⁶⁶

Numerous witnesses testified about the significance of this shift of focus, including Jean-Pierre Galipeault, owner of the Empowerment Connection in Dartmouth, Nova Scotia, who gave the Committee a sense of the far-reaching implications of adopting a recovery framework:

*There are different definitions of recovery, but my business, The Empowerment Connection, defines recovery as, "[o]ccurring when a person's psychiatric diagnosis or emotional and psychological trauma is no longer the central focus in that person's life, but simply becomes a part of who that person is." We must remember that people also have to face the task of recovering from the effects of external and internalized stigma, learned helplessness, institutionalization, poverty, homelessness and the wounds of a broken spirit.*⁶⁷

The histories of people diagnosed with a mental illness are extremely varied; a wide variety of treatments, services and supports can assist recovery. For most consumers of mental health services it is their family physician who is the first, and often only, port of call.⁶⁸ Having access to psychiatrists, psychologists, nurses and other health professionals can also make an invaluable contribution to the well-being of people living with mental illness. At the

⁶⁵ The Committee acknowledges that there is a wide-ranging debate surrounding the applicability of the term "recovery" to some disorders, particularly autism. The Committee heard from a number of passionate advocates for autistic people that recovery is not their goal, because they do not consider autism to be an illness from which recovery is necessary (see also Chapter 6 on Children and Youth for more discussion of issues relating to autism). This is not an issue that the Committee can decide. It will therefore use the term recovery in the way described in this chapter.

⁶⁶ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁶⁷ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁶⁸ Macfarlane D. (June 2005) Current state of collaborative mental health care, p. 5. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario. Available at: <http://www.ccmhi.ca>.

same time, witnesses also pointed to the need for other kinds of services and supports to be available, as Raymond Cheng (a consumer and peer advisor) noted:

*...what people need sometimes is a safe and comfortable place, open at hours they want, accessible to their needs, and having a feeling of community and sharing food, talking to one another, laughing together, and helping one another.*⁶⁹

Recovery has increasingly been embraced within the broader mental health sector,⁷⁰ as well as in government circles. For example, as the Committee noted in its review of mental health policies and programs in other countries, the goal of fostering recovery was placed at the centre of a recent national mental health report in the United States.⁷¹ In practical terms, one of the attractions of a recovery orientation is that it may help create a framework within which services can be meaningfully measured and evaluated.⁷²

3.2.1 The Need for a Recovery-Oriented System

Two models of recovery have been developed: the Psychosocial Rehabilitation Model and the Empowerment Model. The first arose within the professional community, while the second has largely come from the consumer advocacy movement. Although the two models are similar in some respects, there are also important differences. Often used interchangeably by planners, depending on how they are applied the philosophical differences between the models can result in the development of different approaches in service delivery. The two models are described in more detail in the appendix to this chapter.

Very broadly, recovery suggests that the goal of mental health policy should be to enable people to live the most satisfying, hopeful, and productive life consistent with the limitations caused by their illness.

Drawing on these two models,⁷³ the Committee has concluded that a policy approach based on the idea of recovery must acknowledge the following:

- Each person's path to recovery is unique;
- Recovery is a process, not an end point;
- Recovery is an active process, in which the individual takes responsibility for the outcome, with success depending primarily on collaboration among helping friends, family, the community, and professional supports.

⁶⁹ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁷⁰ Provincial Forum of Mental Health Implementation Task Force Chairs. (December 2002) *The Time Is Now: Themes And Recommendations For Mental Health Reform In Ontario*. http://www.health.gov.on.ca/english/providers/pub/mhitf/provincial_forum/provincial_forum.pdf.

⁷¹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) *Report 2 — Mental Health, Mental Illness and Addiction: Mental Health Policies and Programs in Selected Countries*, Ch. 4, p. 71.

⁷² Canadian Mental Health Association, Ontario Division. (March 2003) *Recovery Rediscovered*.

⁷³ See appendix to this chapter. Also Jacobson, N., and Curtis, L. (2000) *Recovery as Policy in Mental Health Services: Strategies emerging from the States*. *Psychiatric Rehabilitation Journal*, Vol. 23, No. 4.

Recovery is about hope. As we noted earlier, recovery does not necessarily equate with cure. It can mean different things to different people. Very broadly, it suggests that the goal of mental health policy should be to enable people to live the most satisfying, hopeful, and productive life consistent with the limitations caused by their illness. For some, recovery will equate to the reduction or complete remission of symptoms related to mental illness.

Recovery allows us to define the role of the system: it is to facilitate the ability of people living with mental illness to deal actively with the limits imposed by their conditions.

A recovery-oriented system must rest upon three pillars: choice, community and integration.

In the past, much of mental health planning has not focused sufficiently on the outcomes achieved by people using the services provided within the mental health system. Recovery provides a focus for re-orienting the design and delivery of mental health programs, services and supports. Importantly, it allows us to define the role of the system: it is to facilitate the ability of people living with mental illness to deal actively with the limits imposed by their conditions.

As Darrell Burnham, Executive Director of the Coast Mental Health Foundation, told the Committee:

The path to recovery is not clearly drawn in a map. We see it as a very person-centred approach; that people will have their own way back into society. The system needs to foster that and facilitate that rather than deliver a specific program that may prejudice that path.⁷⁴

Working toward a recovery-focused system is a complex undertaking. It involves coordinated action by governments at all levels, and at each level there are multiple ministries, agencies or departments, each usually having only minimal awareness of what the others are doing. It involves tens of thousands of providers working both inside and outside the formal mental health care system, some paid within the public system and others not, as well as hundreds of thousands of unpaid caregivers, using whatever resources they can find to help their friends and loved ones, volunteering their time and energy when they can.

There is always the danger that the idea of recovery will be embraced rhetorically but not translated into policy and action.⁷⁵ In the next three sections of this chapter, a bridge is suggested between the notion of recovery and the specific proposals for reform contained in the remaining chapters of this report. In the Committee's view, a recovery-oriented system must rest upon three pillars:

⁷⁴ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁷⁵ In the broader health care field, one can think of the issue of primary care reform as offering a cautionary tale in this regard. For over a decade, every major report on the hospital and doctor system in Canada has pointed to the need for significant reform to the ways in which primary health care is delivered, but progress on the ground has been very slow.

- **Choice:** Access to a wide range of publicly funded services and supports that offer people living with mental illness the opportunity to choose those that will benefit them most;
- **Community:** Making these services and supports available in the communities where people live, and orienting them toward supporting people living in the community;
- **Integration:** Integrating all types of services and supports across the many levels of government and across both the public/private divide and the professional/non-professional dichotomy.

3.3 CHOICE

In general, the range of choices that have been available to consumers of mental health services has been severely limited. The system has lacked both the resource capacity and the flexibility to provide personalized services that engage individuals in their own recovery, whether they are seeking treatment in an acute inpatient ward or living in their communities.

It is people living with mental illness themselves who should be, to the maximum extent possible, the final arbiters of the services that are made available within the overall mental health system and of the ways in which they are delivered.

This is how Darrell Downton, Co-Chair of the Mental Health and Addictions Advisory Committee of the Five Hills Health Region in Saskatchewan, put it in his testimony to the Committee:

The limited options available to people with mental illness and addictions confirm to them that they are not eligible to receive the care and support they deserve. Their recovery is limited by the options available.⁷⁶

Viewed from the perspective of fostering recovery, choice is both a means to an end — a more responsive service — and also an end in itself. This is because being able to make choices is a manifestation of the rights and responsibilities of adulthood, and of full citizenship. The availability and exercise of choice is itself a potential contributor to the recovery process.

Current funding arrangements mean, therefore, that many services needed by people living with mental illness and addiction are available only to those who can pay for them out of their own pockets, or who have private insurance plans that cover them.

The Committee believes that it is people living with mental illness themselves who should be, to the maximum extent possible, the final arbiters of the services that are made available within the overall mental health system and of the ways in which they are delivered. In this sense, it is legitimate to speak in terms of encouraging a consumer-driven, or consumer choice, approach.

⁷⁶ 2 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

This is the best way both to encourage the elaboration and implementation of practical solutions to the problems encountered by people living with mental illness and addiction, and to promote the mental well-being of the population as a whole. No single body, least of all a governmental one, should be so arrogant as to believe it can prescribe a universal treatment model for all people living with mental illnesses and addictions.

Furthermore, no single treatment model should be allowed to dominate the policy horizon, either in theory or in practice. Many people will find successful treatments or care that are derived from a purely “medical” model, while others will look to their particular community or cultural traditions for ways of achieving the best mental health possible.

Moreover, because of the complexity of mental illnesses and their intimate connection with each individual’s unique circumstances and environment, many will find that they will need to draw on treatments, supports and ways of caring that combine elements drawn from multiple approaches.

Allowing people a range of choices that can be based in a variety of traditions is not merely the expression of a philosophical preference — it has important national policy implications. It points to the need to address the fact that an institutionalized bias is built into the way public funding for health care services works in Canada: under the *Canada Health Act*, only services that are provided by physicians or in hospitals are *required* to be publicly funded.⁷⁷

While other services may be funded by individual provinces or even at the community level, access to them will vary widely. Current funding arrangements mean, therefore, that many services needed by people living with mental illness and addiction are available only to those who can pay for them out of their own pockets, or who have private insurance plans that cover them.

The services provided by psychologists are one example that the Committee heard repeatedly. As one e-consultation respondent argued:

The biomedical model does not address underlying issues like abuse. I believe the origin of my illness is from childhood incest. Childhood sexual abuse has devastating consequences to a person's life. A huge percentage of people diagnosed with Borderline Personality Disorder have suffered sexual abuse. I can not afford to pay a psychologist \$150 an hour to treat me. The most important thing I need is therapy. —Anonymous

This was echoed by another respondent:

Ever since the “revolution” in drug treatment for psychiatric disorders, psychiatrists have gradually dropped their role as psychotherapists. Psychotherapy is only covered by my provincial health plan if provided by a psychiatrist (as a medical doctor). I have taken far more medication than I

⁷⁷ See Standing Senate Committee on Social Affairs, Science and Technology. (October 2002) *The Health of Canadians — The Federal Role, Volume Six: Recommendations for Reform*, Ch. 17. Note that specialized psychiatric hospitals were explicitly excluded from the purview of the *Canada Health Act* because they were deemed to be long-term care facilities whose regulation was not the intent of the Act.

would have liked at an exorbitant cost to my health and to my provincial health plan, when I could have done with much less medication and had a far quicker recovery had I been able to afford psychotherapy. If the provincial plan had paid for my psychotherapy I believe that they would have saved money and my overall mental and physical health would be better as a result.
—Anonymous

Providing people living with mental illness with access to a full range of services and supports in addition to those provided by physicians and hospitals, and enabling them to select freely the ones they prefer, requires that an adequate range of services be made available and that people have available the funds to pay for them.

The Committee is aware that creating the conditions to sustain an environment that allows people living with mental illness to choose those services that benefit them most will not be easy. There will always be hard policy decisions to be made about how public resources can best be used. Moreover, no one can expect that all options will ever be freely available for everyone who desires them.

On the one hand, this means that policy decisions about which services and supports should be widely available and accessible to those who would choose them must be made on the basis of the best available evidence as to their effectiveness. Given the multiple dimensions implicated in mental health issues (social, environmental, medical, biological), it is necessary to apply a methodological pluralism to the selection and evaluation of the evidence of effectiveness itself. Relevant findings derived from the medical sciences, social sciences, and from people with direct experience of mental illness must all count in weighing such evidence.

Consumers of mental health services and supports (...) must be heard at the policy table, just as they should be allowed to make individual choices about which services and supports are right for them.

On the other hand, the need to collectively set the priorities for public spending points to another dimension of fostering choice. Consumers of mental health services and supports must be given the opportunity to participate actively in the process of collective decision-making. Their collective voice must be heard at the policy table, just as they should be allowed to make individual choices about which services and supports are right for them.

3.4 COMMUNITY

An orientation to providing access to community-based services and supports is the second pillar needed to support the creation of a recovery-oriented system. The evidence is clear that the shift begun many years ago away from institutionalized models of care was the right one, even if it was not always sufficiently resourced in practice.

An orientation to providing access to community-based services and supports is the second pillar needed to support the creation of a recovery-oriented system.

Many witnesses stressed the importance of this community-based orientation:

In all the literature I have read about recovery, every person who discloses on this topic says that connection to the recovery community is the most important fact of ongoing recovery. Otherwise, relapse is particularly inevitable — sending the person back into a poorly functioning state. —Patricia Commins⁷⁸

Others pointed to the range of resources required in the community to support and sustain the recovery process. Geoff Chaulk, Executive Director of the Newfoundland and Labrador division of the Canadian Mental Health Association, told the Committee:

The community resource-based model with the person at the centre of the system also addresses the essential elements for successful community living and recovery, including adequate housing and income, work, social connections and mental health services and supports.⁷⁹

Since mental health and addiction problems cut across so many facets of community life, much more than health care and other publicly funded social services will be required to respond properly. A wide variety of forms of community action make meaningful contributions to people affected by mental illness and addiction; without them, publicly funded services would be left to struggle with an overwhelming challenge. In addition, by making the community the focus for service provision, people can stay close to their personal support networks.

For people living with serious mental illness, there is strong evidence that with the proper supports in place they can not only live in the community but also lead fulfilling and productive lives.

But Dr. Paul Garfinkel, CEO of the Centre for Addiction and Mental Health, cautioned that:

...community care is not cheap care. Community care requires specialized resources with knowledgeable people who provide care and treatment. We have a treatment program for psychosis involving 100 people with schizophrenia. Our team goes out to the homes in Toronto and keeps these people at home, very successfully. It is an excellent treatment program. It involves 100 people who, for sure, would have been in hospital. However, it is expensive. You need a doctor. You need a nurse. You need a social worker. You need a whole team.⁸⁰

The significance of basing mental health services and supports in the community holds for people living with all types of mental illnesses, from the mildest to the most severe. But the mechanisms through which the needed services and supports are best delivered will vary according to the severity of people's illnesses as well as their individual capacities to cope with the limitations imposed on them by their illnesses.

⁷⁸ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁷⁹ 15 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁸⁰ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

For people living with serious mental illness, there is strong evidence that with the proper supports in place they can not only live in the community but also lead fulfilling and productive lives.

A recent report by the Community Mental Health Evaluation Initiative in Ontario, for example, concluded that programs such as Intensive Case Management or Assertive Community Treatment that are designed to assist people living with serious mental illness to remain in the community were “helping clients decrease their reliance on institutional care and improve their quality of life.”⁸¹

The same report referred to data from a study done in Ottawa that indicate that:

...on average, it costs about \$68 per day to provide community-based services to a person with mental illness. To treat the same person in hospital, however, would cost \$481 per day.⁸²

Of course, hospital services will always be an essential component in the continuum of care. Nonetheless, another study, from the Eastern Townships region of Quebec, showed that, by providing appropriate community-based facilities, it was possible for a region of close to 300,000 people to meet the long-term needs of people living with serious mental illness in a region that has never had a specialized psychiatric institution.⁸³

An orientation towards the community will mean something different for people experiencing mild to moderate mental health problems. For most of them, contact with the mental health system will occur through a primary health care provider (group or solo), who may or may not connect them subsequently with a specialized mental health service of some kind.

Epidemiological data indicate that, each year, roughly 3% of the population will experience a serious mental illness, and that another 17% or so will experience mild to moderate illness. The full range of services must be available therefore to address the needs of both broad categories of people. Figure 1 provides a graphic representation of a system that places individuals at its centre, and of the types of treatments, supports and services that must be in place to meet the needs of all people who experience mental health problems.

The most appropriate balance among all the various elements will vary from community to community and will likely evolve as more becomes known about what types of intervention genuinely facilitate recovery among those living with the complete range of mental illnesses. However, the starting point for thinking about how to improve the mental health system should be the main types of mental health treatments, supports and services that are currently being deployed. This is what is captured in Figure 1.

⁸¹ Ontario’s Community Mental Health Evaluation Initiative. (October 2004) Making a Difference, p. 5.

⁸² *Ibid.*, p. 9.

⁸³ Trudel, J.-F., and Lesage, A. (2005) Le sort des patients souffrant de troubles mentaux très graves et persistants lorsqu’il n’y a pas d’hôpital psychiatrique: étude de cas. *Santé Mentale au Québec*, Vol. XXX, No. 1, pp. 47-71.

3.5 INTEGRATION

The separation between services and supports that are delivered through the health care system and those that fall largely under other spheres of responsibility, as illustrated in Figure 1, points to the fact that many institutional and structural roadblocks stand in the way of realizing a “seamless” delivery of mental health supports and services.

On the one hand, within the health sector, mental health services must be integrated with physical health care services. Ways must be found to improve the diagnosis and treatment of many illnesses at the level of primary care, as well as ways to integrate better specialist care with primary care services.

Many institutional and structural roadblocks stand in the way of realizing a “seamless” delivery of mental health supports and services.

On the other hand, the variety of mental health treatments and services funded by ministries of health must also be integrated with the broader range of services required by people living with mental illness that are the responsibility of the various governmental departments and agencies that deal with income support, housing, employment, etc. Moreover, it is essential that services and supports for people living with both mental illness and addiction be better integrated.

The variety of mental health treatments and services funded by ministries of health must also be integrated with the broader range of services required by people living with mental illness.

Integration also requires that services and supports will be available to people throughout their lifespan.

Finally, integration also requires that services and supports will be available to people throughout their lifespan, and that as people’s needs change as a result of aging or circumstances they will still be able to gain access to appropriate services and supports in a “seamless” fashion.

Many challenges must be met to achieve the integration of services and supports that many witnesses insisted was essential to improving access to required services and building a system that encourages recovery. First amongst these is the recognition that integration can take place in many ways, and that it is important therefore to adapt strategies to achieve integration in ways that are appropriate to each community’s particular situation.

In this regard, a report prepared by researchers at the Centre for Addiction and Mental Health, *Strategies for Mental Health Integration*, points out the numerous dimensions to the problem of integrating mental health services. It cites research underlining the need to distinguish among three domains — governance, administration and service delivery.

Governance refers to the part of the system with accountability for system performance and the authority to set strategic direction and policy and to oversee general management and the use of resources. Administration is the domain that supports operations on a daily basis and includes the infrastructure for finance, information, human resources, etc. Service is that part of the organization that provides services and supports directly to consumers.

The report notes that the intensity of integration can vary from loosely connected alliances to highly integrated organizations, as can the degree of formality involved (ranging from informal or verbal agreements to formal policies, rules and procedures).⁸⁴ The evidence summarized in the report suggests that it is difficult to draw definitive conclusions regarding the ideal way to achieve integration or system-building. It does not appear that integration is best pursued as a cost-saving measure, or that all approaches to system integration yield the desired results.

Nonetheless, a number of benefits were identified that can be derived from greater integration of mental health services, noting that several studies have demonstrated the positive effects of initiatives where:⁸⁵

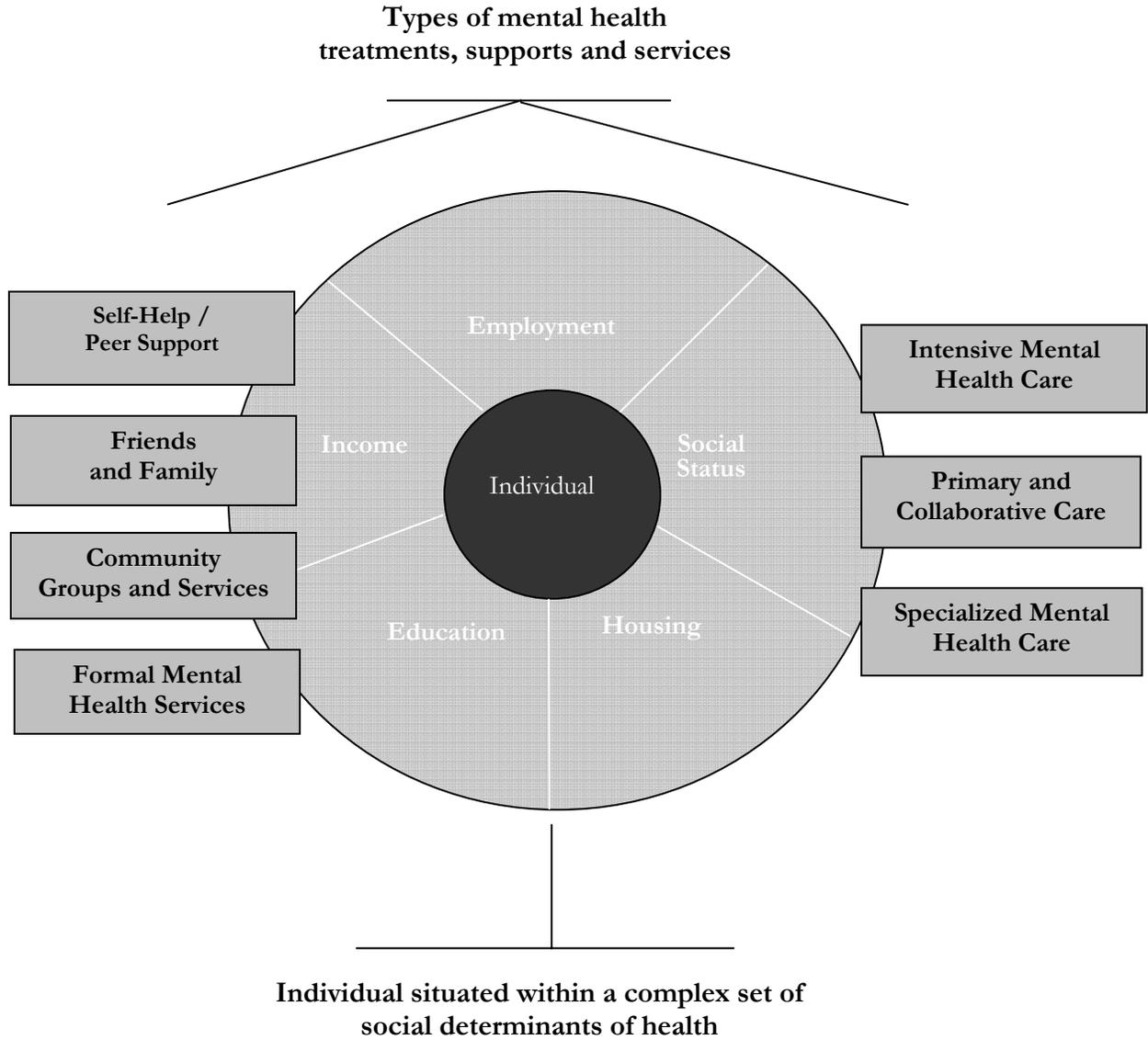
- a system manager controls a pooled funding envelope;
- performance targets are set and monitored;
- organization of services in the network is centralized around a core (but not necessarily consolidated) agency;
- the system manager has control over inpatient services and monitors admissions.

⁸⁴ Centre for Addiction and Mental Health. (2001) *Strategies for Mental Health Integration: A Review*, p. 13.

⁸⁵ *Ibid.*

Figure 1

Source: Adapted from New Brunswick Department of Health and Wellness, *Community Mental Health Centres: Programs and Services*, p. 3, accessed at: <http://www.gnb.ca/0055/cmhcs-e.asp>



Others have also commented on the fundamental challenges involved in changing governance structures in the broader health care sector. Mintzberg and Glouberman, for example, have noted that:

Clinical activities cannot be coordinated by managerial interventions — not by outside bosses or coordinators, not by administrative systems, not by discussions of “quality” disconnected from the delivery of it, not by all that constant reorganizing... *Management of clinical operations will have to be effected by the managed, not the managers.*⁸⁶

In March 2000, Ontario’s Health Services Restructuring Commission (HSRC), chaired by Duncan Sinclair, published a report reflecting on its mandate and attempts to restructure the hospital system in Ontario. The HSRC made the following observations about organizational change and governance:

It is important to allow regions and communities to pursue forms of integration that are appropriate to their particular situations.

- There is no one best system/ model of governance, but “there is a need to find better ways to promote greater integration, efficiencies and effectiveness across the various components of the health system.”
- New governance models should emerge which “allow individual organizations to use their strengths and talents” while preserving and enhancing organizational distinctiveness.⁸⁷

Finally, in a paper on “Mandated Collaboration,” Steve Lurie looked at the implications for mental health reform of the fact that “there is limited evidence that structural or organizational reform improves clinical outcomes.”⁸⁸ The general lessons he drew with regard to efforts at system integration include the following:

- one size doesn’t fit all
- use best practices and unified funding models to drive system change
- there is a need to attend to corporate culture and human resource issues if attempting structural change or alliance building

⁸⁶ Glouberman, S. and Mintzberg, H. (Winter 2001) Managing the Care of Health and the Cure of Disease, Parts I and II. In *Health Care Management Review*, Vol. 26, Issue 1, pp. 72-4 (emphasis added). Everett, B., Lurie, S. and Higgins, C. (2001). *The Whole Picture: A provincial framework for redesigning the Ontario mental health system*. Canadian Mental Health Association, Ontario Division, and Ontario Federation of Community Mental Health and Addiction Programs.

⁸⁷ Ontario Health Services Restructuring Commission. (2000) *A Legacy Report: Looking Back, Looking Forward*. Quoted in Everett, Lurie, and Higgins (2001).

⁸⁸ Lurie, S. (June 2002) *Mandated Collaboration: Command and Control or Emergent Process*. Canadian Mental Health Association, Metro Toronto Branch, p. 37.

- Rome wasn't built in a day; the development of effective collaborative relationships take time
- there is a need to experiment, evaluate and learn from experience

It is possible to identify many potential ways of improving integration of mental health services and supports. A partial list could include:

- expanding the use of multidisciplinary teams, shared care and collaborative care arrangements
- developing common assessment protocols
- pooling funding
- putting in place registries of available services
- linking data systems and electronic health records
- creating mental health authorities or engaging in area planning
- developing common service protocols and care pathways

The Committee believes that it is important to allow regions and communities to pursue forms of integration that are appropriate to their particular situations. Each community and region will have to choose strategies that take into account its readiness for change, and the available opportunities for improving access to services.

It is critical that integration be recognized as an essential dimension of building a recovery-oriented mental health system.

For example, we will later describe some of the ways that mental health services have been successfully integrated in Brandon, Manitoba. While Brandon's experience is exemplary in many ways, it is also clear that it would be extremely difficult to replicate that experience precisely in other communities across the country. Not only has it taken 25 years of hard work by a dedicated group of people in Brandon to restructure and coordinate their community mental health services, but their success is also built upon a very particular history of deinstitutionalization that provided a context for change that does not exist in many other communities. Nevertheless, a lot can be learned from that experience.

While the approach to integration must be based on the particular history and circumstances of each community, it is still critical that integration be recognized as an essential dimension of building a recovery-oriented mental health system. Integration in some fashion is an indispensable ingredient to provide people living with mental illness and addiction with a truly seamless delivery system that can meet their needs throughout their lifespan.

While there will never be a single template for how this is to be accomplished, the goal of recovery is one that must drive efforts to reform the mental health system. Integration must be seen as a means to achieving that goal and not as an end in itself — it must serve the

objective of improving the range, affordability, quality, and accessibility of services. This requires measurement, accountability, and a commitment to change.

3.6 TURNING THE VISION INTO REALITY

The remainder of this report will describe the changes required if progress is to be made in creating a recovery-oriented mental health system that rests firmly on the three pillars of choice, community and integration. There are many concrete hurdles to be overcome, many of which were documented in the Committee's background reports and eloquently recapitulated in the testimony of the witnesses and participants in the Committee's e-consultations who were quoted in the first two chapters of this report.

At times the task can seem overwhelming, in part because making progress in any one area seems to depend on making progress in them all. The Committee firmly believes that despite the scale of the challenge it is possible to move forward, but only if a strategic plan is developed and a step-by-step approach is adopted toward its implementation. We recognize that it is indeed impossible to transform the entire mental health delivery system in one fell swoop. However, pragmatic reform that enables real improvements to be made in the lives of people living with mental illness and addiction is achievable and it must happen, and soon.

The Committee firmly believes that despite the scale of the challenge it is possible to move forward, but only if a strategic plan is developed and a step-by-step approach is adopted toward its implementation.

The Committee is acutely aware that this report will not contain all the answers to the many challenges that confront many thousands of Canadians concerned with mental health and addiction. A parliamentary report in itself can never guarantee that action on its recommendations will follow. Moreover, the effort to implement a reform plan must extend over a considerable period of time.⁸⁹

Nevertheless, the Committee has been encouraged in the course of its public hearings by the sense that the time may just be right to move forward in key areas. Moreover, as will become apparent, the Committee has worked very hard to ensure that the momentum for change that has been building during the three years in which we have been working on this issue can be sustained. In this regard, one of the recommendations in this report (see Chapter 16) stands out as key to the process of transforming the mental health delivery system in Canada.

⁸⁹ In this regard, the Committee takes note of the fact that even in countries such as Australia that have set an international standard in mental health planning, there are indications of how difficult it is to sustain the momentum for reform. In a recent (May 2005) report to a parliamentary committee titled *Not a Failure of Policy, It Is a Failure of Implementation and Delivery*, the Mental Health Commission of Australia writes that "the last five or six years have seen what was a significant policy initiative lose direction and show signs of stress and indeed crisis." It identifies a number of causes for this evolution, including: (a) "the burden of mental illness and associated disability within the community is not matched by the funding allocated to prevent, relieve and rehabilitate people experiencing mental health illness"; (b) "there is a significant mismatch between the community based mental health service model and the current system of still allocating funding largely on the old service model of 'beds and buildings'; and (c) "the failure to agree on and implement a national framework for accountability."

The Committee believes that only if the Canadian Mental Health Commission, recommended in Chapter 16, is created immediately following the release of this report, will it be possible to maintain a national focus on mental health issues and bring together all the stakeholders who will have a role to play in transforming the system. In this sense, the new Canadian Mental Health Commission is an essential mechanism for the realization of the vision outlined in this chapter and for implementing the reform measures described and recommended in the rest of this report.

3.7 SUMMARY OF PRINCIPLES

The principles outlined in this chapter can be summarized as follows:

1. While mental illness and physical illness are both like and unlike each other, they must be treated with **equal** seriousness, and people who are living with mental and physical illnesses must be accorded **equal** respect and consideration.
2. The central goal of mental health policy is to create the best possible context for encouraging **recovery**; a focus on recovery places emphasis on wellness as opposed to illness, and sets the goal of facilitating the abilities of people living with mental illness to deal actively with the limits imposed by their conditions and to live meaningful and productive lives.
3. Promoting mental health and recovery from mental illness **requires** interventions that address the **social determinants of health** — in particular those related to income, adequate housing and employment, and participation in social networks.
4. A policy approach based on the idea of recovery must acknowledge that:
 - Each person’s path to recovery is unique;
 - Recovery is a process, not an end point;
 - Recovery is an active process in which the individual takes responsibility for his or her own recovery, and success depends upon collaboration among helping friends, family, the community, and professional supports.
5. A focus on recovery will require reorienting the design and delivery of mental health programs; there are three pillars upon which a recovery-oriented system must be founded:
 - **Choice:** Access to a wide range of publicly funded services and supports that offer people living with mental illness the opportunity to choose those that will benefit them most;
 - **Community:** Making these services and supports available in the communities where people live and orienting them toward supporting people living in the community;

- **Integration:** Integration of all types of services and supports across the many levels of government, and across both the public/private and the professional/non-professional divides.
6. Policy decisions about which treatments, services and supports should receive public funding must be based on the best evidence available; this includes findings from the medical sciences, data and analyses from the social sciences, and the testimony of people with direct experience of mental illness.

APPENDIX: MODELS OF RECOVERY

1) Psychosocial Rehabilitation Model

The most widely used rehabilitation model is the Psychosocial Rehabilitation Model (PSR) originated in Boston University.

PSR is a professionally driven model that has shaped the development of many community-based programs and services.⁹⁰ It is based on the view that people with a mental illness can recover even though their illness is not cured. PSR focuses on enhancing functional ability and attempts to look at all areas of a person's life, including strengths, resources, and barriers. The PSR approach seeks to improve four main life domains:

- practical skills of personal self-care,
- home management,
- relationships and use of community resources,
- leisure, education, and employment.

The goal is to help people regain social functioning despite their having symptoms, limitations and taking medications. The PSR specialist helps the individual move toward self-selected meaningful life goals and provides appropriate social and therapeutic supports to help them do so. Goal-specific skills are taught to assist individuals to achieve self-sufficiency, building on natural social and community support systems.

Within this model, mental illness is seen as a permanent impairment similar to the way a spinal cord injury produces lasting paralysis. It is considered that people have a "broken brain" and that, with appropriate and adequate supports, they can continue to function in society. However, their impairment remains permanent.⁹¹

The fundamental principles that underpin PSR can be stated as follows. PSR:

1. Emphasizes the need for individually tailored interventions;
2. Requires either that the individual's capacities be adapted to environmental realities or that the environment be changed to suit the capacities of the individual;
3. Builds on the individual's strengths;
4. Aims to restore hope;
5. Emphasizes the individual's vocational potential;
6. Extends beyond work activities to encompass a full array of social and recreational activities;
7. Actively involves individuals in their own care;
8. Is an ongoing process that must continue over time.

⁹⁰ Jacobson, N., and Curtis, L. (2000) Recovery as Policy in Mental Health Services: Strategies emerging from the States. *Psychiatric Rehabilitation Journal*, Vol. 23, No. 4.

⁹¹ *Ibid.*

Psychosocial rehabilitation focuses on early intervention, wellness, independence, self-determination and most importantly — hope. Cognitive therapy, or the process of learning positive and self-enhancing self-talk, is used to help people make sense of and manage distressing symptoms of illness. Mutual support, through peer support groups, is seen to enhance self-sufficiency and expand social networks, build each person’s self-reliance and overcome dependency on professionals.

The belief in the client’s personal capacity for growth, the development of helpful partnerships and seamless services built on individual needs and preferences are core to the psychosocial model. Clients receive ongoing evaluation to ensure continuous progress.

Strategies include illness education, family intervention, supported employment, assertive community treatment (ACT), skills training, and cognitive behavioural therapy.

The practice of psychosocial rehabilitation is done by existing professionals such as psychiatrists, psychologists, social workers, occupational therapists and nurses, all with the necessary skills and training, or by persons who have received specific training in psychosocial rehabilitation in university programs.

The “client-centred” approach utilized by PSR specialists has been criticized at times for “colonizing” the life of consumers where professionals are actively involved not only during periods of sickness but when people are healthy as well. There have been instances where professionals have claimed ownership and responsibility not only for illness management but for social, recreational and employment roles as well. This has prompted some consumers to react by saying that “*When you say ‘client-centred’, I feel surrounded.*”⁹²

Dr. William Anthony, the “founder” of the psychosocial rehabilitation movement, emphasizes that recovery can occur without professional intervention. The task for professionals is to facilitate this natural process.⁹³ He named the 1990s the “decade of recovery” because of the gains made in helping people adjust to community living. However, he cautions that 2000 must be the “decade of the person.”

In his view, rehabilitation must be done “with” clients, not “to” them. He believes people can make meaningful choices and recognizes that lip service has been paid to the concept of self-determination. The belief that people with mental illness set unrealistic goals and cannot hold demanding jobs has resulted in professionals taking choices away from consumers “for their own good.” In his words, “If people are allowed to choose they may request something that demands we change our actions or programs.”⁹⁴

⁹² Canadian Collaborative Mental Health Initiative. (2004) Ontario consumer consultations.

⁹³ Anthony, W. A. (1993) Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, Vol. 16, pp. 11-23.

⁹⁴ Anthony, W. A. (2003) The Decade of the Person and the Walls that Divide Us. *Behavioural Healthcare Tomorrow*. <http://www.bu.edu/cpr/catalog/articles/2003/anthony2003c.pdf>.

2) Empowerment Model

The consumer advocacy community has championed the empowerment model of Recovery as a means of promoting the idea that psychiatric patients are able to work and live independent lives and should not be defined by their “diagnosis.” Proponents of the empowerment model argue that designating mental illness as a permanent condition is one of the factors that contribute to ostracizing people living with mental illness from society.⁹⁵

For consumer activists, recovery has political as well as personal implications — it is a philosophy with a set of organizing principles and values which can guide the development of supports and services as well as how they are organized and delivered.

On this understanding, to recover is to reclaim one’s life, to be validated as an autonomous, competent individual. It emphasizes that people are responsible for their own lives and affords them the privilege of choice, including the right to make mistakes. Moreover, it insists that professionals cannot manufacture the spirit of recovery.

As one e-consultation respondent told the Committee:

Systemic change will not come from professionals who experience these illnesses through an academic lens but from the lived experience of consumers and families. Ask a professional what is needed and they will always say more professional service. Ask a consumer and family member and they wish and hope for recovery. To be part of the community, a contributing and valued member of society with friends and [a] safe home. No amount of medication will help achieve those goals. Although for many medication is vitally important for clearing the path to wellness. —Anonymous

Recovery is understood as a manifestation of personal empowerment. Within this framework, recovery happens when there is a combination of supports to (re)establish social function and sufficient self-management skills to take control of the major decisions affecting one’s life.⁹⁶

According to the Empowerment Connection:

Recovery is the lived experience of persons as they discover, accept, and overcome the challenges of a disability, the effects of a psychiatric diagnosis or emotional or psychological trauma. It is discovering a new sense of self, of hope and purpose within and beyond the limits of these experiences. It is the discovery of one’s own strengths and sense of power and control within oneself and the world. Finally, recovery occurs when a person’s psychiatric diagnosis or emotional trauma is no longer the central focus in that person’s life, but simply becomes a part of who that person is.

⁹⁵ Fisher, D. B. (1999) A New Vision of Recovery: People can fully recover from mental illness; it is not a life-long process. National Empowerment Centre.

http://www.power2u.org/recovery/new_vision.html.

⁹⁶ *Ibid.*

It is not just mental illness and psychological trauma that people have to recover from; they also face the task of recovering from the effects of internalized stigma, learned helplessness, institutionalization, poverty, homelessness, and the wounds of spirit breaking.⁹⁷

Empowerment recovery is a values-based approach that puts people first and holds that the experience of illness is not permanent. This means that not only is recovery possible, it is to be expected. Recovery is seen as a continuing internal process that places the person at the centre of his or her own recovery. It is not seen as a linear process with an end point or destination. This approach to recovery also holds that individuals are “expert” in their own care. The re-establishment of social relationships is seen as vital to recovery, particularly with peers who understand viscerally the experience of mental illness.⁹⁸

Empowerment recovery does not suggest that professional services are unimportant or unnecessary. However, such services are not intended to “fix” the person, but rather to support him or her as the individual moves towards a healthy life. Individuals living with mental illness are seen as the agents of change, and professionals are one of the resources to be drawn upon. In this model, psychiatric treatment is viewed as part of self-managed care.

Adopting such an approach implies a shift away from the goal of treatment being the stabilization of illness through symptom reduction. Instead, the goal becomes to assist people to gain greater independence and control over their own lives. Medication is used as a tool to help people reach that goal — not as a solution to their problems. The continued use of medication does not preclude recovery. Rather it is seen as a useful adjunct to help people gain control when they are frightened or confused.

Within this recovery model, supports and services can be accessed without requiring the acceptance of the diagnostic (labelling) process. Professionals help to foster recovery by believing in the capacity of their clients to heal and by acknowledging their right to make decisions, even at the risk of failure. Demanding compliance and conformity with professional authority is considered to interfere with learning how to become self-determining. An essential ingredient of recovery is hope. Recovery requires that everyone be given a chance to get better, at their own pace. The recovery approach asks people what they want and need in order to grow, and provides them with the skills and supports to achieve it.⁹⁹

Changing the relationship between those who have been labelled “mentally ill” and those who have not can also create a common ground. Accepting the possibility that any one of us can experience a mental illness, that, in the words of Dr. John Frank, Scientific Director

⁹⁷ <http://www.empowermentconnection.com/approach.html>.

⁹⁸ An Empowerment Model of Recovery from Severe Mental Illness: An Expert Interview with Daniel B. Fisher, MD, PhD. (January 2005) *Medscape, Psychiatry & Mental Health*, Vol. 10, No. 1.

⁹⁹ Deegan, P. (1996) *Recovery and the Conspiracy of Hope*. 6th Annual Mental Health Services Conference of Australia.

of the Institute of Population and Public Health, we “are all at risk at different times in our lives,”¹⁰⁰ helps to remove the stigma engendered through seeing it as “them” and “us.”

Each person’s path to recovery is unique, and what fosters recovery reflects personal experiences and preferences. Recovery may include 12-step programs, developing close, supportive, and mutual friendships, intermittent or ongoing treatment, participation in social or vocational rehabilitation programs, becoming involved in spiritual communities, and/or consumer-/survivor-run support networks and advocacy groups. Power and responsibility must be shared by actively involving consumers and family as key players in mental health planning, organizational governance, system design, evaluation, and service delivery.

Recovery-oriented systems recognize that concepts of recovery need to be taught and create educational opportunities such as workshops and conferences for policy makers, planners, professionals, consumers and family. Consumers are seen as recovery educators. A recovery model would ensure that a percentage of funding is allocated for consumer-run initiatives and support such as peer support, self-help, and economic development initiatives, as well as crisis and respite care programs. It includes recognition that building the capacity for sustained and meaningful participation by consumers and family organizations requires long-term adequate funding, management training, and organizational support to be successful

¹⁰⁰ Gordon, A. (2005) Combating the stigma of mental disorders: New initiative to kick off mental health week. Toronto Star, 29 April 2005.

Accountability means requiring the mental health system to comply with the law. —Jennifer Chambers¹⁰¹

4.1 ACCESS TO PERSONAL HEALTH INFORMATION

4.1.1 Background

The issue of the right to privacy of persons living with mental illness and addiction, and the impact of that right on their family caregivers, has been raised repeatedly by witnesses at public hearings since the Committee began its work over two years ago. In its earlier review of this difficult issue, the Committee noted that:

The Committee is not convinced that the issue of confidentiality represents conflict solely between persons living with mental illness and their family caregivers. The Committee is also sceptical that existing legal protections of the right to privacy of persons living with mental illness are unworkable.

Concern arising from strict observation of privacy and confidentiality rules also extends to the family of individuals with mental illness and addiction. Without the patient's permission, which those with mental illness/addiction may not be competent to give, a physician cannot share personal information with his or her caregivers, parents, siblings or children.¹⁰²

With respect to privacy and confidentiality issues, the Committee is well aware that any erosion of privacy and confidentiality protections can have serious negative consequences on an individual's trust in his or her caregivers. However, as noted above, witnesses have told us that rigid adherence to privacy and confidentiality rules in certain circumstances can work against the interests of individuals whose mental health is compromised. The unique challenges they describe must be recognized when developing, interpreting and applying privacy and confidentiality rules, so as to allow health care providers and family caregivers to provide patients with the much needed support they sometimes require.¹⁰³

¹⁰¹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁰² Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 11, Section 11.3, p. 238.

¹⁰³ *Ibid.*, Chapter 11, Section 11.7, p. 246.

Such was the Committee's concern that in the aftermath of its first round of public hearings, in its third interim report it posed a series of questions to elicit additional comment from the public. Specifically, it asked:

Are there mental health systems that have better, clearer procedures and consent forms for releasing information to families? What changes are required in Canada to facilitate the sharing of information about a patient's/client's condition with his or her family? Should there be greater consistency and standardization of information sharing practices in Canada with respect to patients with mental illness and addiction?¹⁰⁴

In the subsequent public consultations there was extensive comment and debate on this topic and feedback was received from those living with mental illness, and their families. Not surprisingly, no clear consensus emerged.

To illustrate, Ron Carten, Coordinator of the Vancouver-Richmond Mental Health Network, and a person with direct experience of mental illness, stated that:

Regarding children, I do not think confidentiality should be extended to exclude parents. Parents need to know about their children and have a right to know about their children.

Regarding adults, I think we have to treat the mental patient, regardless of his relationship to his family, as an adult and an individual with rights and dignity, and therefore, notwithstanding the family's interests in their family member, confidentiality should stand.¹⁰⁵

Joan Nazif, of the Family Advisory Committee of Vancouver Mental Health Services, presented the opposite view:

A major concern for families is to access information about their seriously mentally ill family member. Family members are not interested in the confidential discussions between therapists and patient but they do need to know the diagnosis, care plan, medication, safety issues, so that they can continue to provide the best support.

[...]

Now, there are instances, I am sure, where families are not therapeutic for the individual. We are family members who love our family member, and we give

¹⁰⁴ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 3 — Mental Health, Mental Illness and Addiction: Issues and Options for Canada, Chapter 6, Section 6.5, p. 45.

¹⁰⁵ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42471-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*support to our loved one 24 hours a day. I mean, I will be there for my daughter as long as I live.*¹⁰⁶

Having regard to all the evidence and opinion, the Committee is not convinced that the issue of confidentiality represents conflict solely between persons living with mental illness and their family caregivers. The Committee is also sceptical that existing legal protections of the right to privacy of persons living with mental illness are unworkable. That is not to say that reform of the laws governing privacy is unnecessary, but that it should not be considered in isolation from the more general debate about transforming the whole mental health system.

4.1.2 Finding a Way Forward

The *Charter* rights of persons living with mental illness and addiction, and in particular their right to equality, must be respected. These affected Canadians are full members of our society. Questions concerning their mental capacity cannot be used as a pretext for watering down or stripping away any of their civil liberties or human rights.

This having been said, the Committee is not insensitive to the circumstances of family caregivers. Many who appeared before the Committee expressed their keen desire to assist and support their loved one in the recovery process. Indeed, it was their forceful and articulate arguments that consistently held this issue at the forefront of our deliberations.

4.1.2.1 Privacy and the Age of Consent

Dealing first with the right to privacy for children and youth, parents want and need full information about the health of their children. The claim of access to personal health information by family caregivers is clearly strengthened when a child is involved. Nevertheless, the Committee appreciates that, prior to achieving the age of majority, some people may be fully capable of deciding who should have access to their personal health information and to what extent.

Given the lack of consistency across Canadian jurisdictions with respect to applicable privacy legislation, and varying capacities on the part of children and youth to consent to their own health treatment, the Committee recommends:

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| 1 | That the provinces and territories establish a uniform age at which youth are deemed capable of consenting to the collection, use and disclosure of their personal health information. |
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¹⁰⁶ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

4.1.2.2 The Role of Health Care Professionals

Some witnesses suggested that health care professionals were not doing enough to ensure that existing legislation governing access to personal health information was applied consistently and to its fullest extent. For example, Brenda McPherson, Provincial Coordinator, Psychiatric Patient Advocate Services, New Brunswick, testified that:

I think we have to open up that door for doctors to say, “Let me look at this. Let me talk with your son, or your daughter, or your mother. Let me try to help this process.”
—Brenda McPherson

In terms of parents having information, health professionals need to be more informed about how they need to play an active role in getting consent from patients. It is a matter of signing your name on a piece of paper and saying, “Yes, it is okay for my doctor to talk with my parents.”

I think we tend to overdramatize the issue of consent, and we should stop doing that. Health care professionals need to understand the importance of that. Maybe we need to open up that door, and ask, how can we best educate our health professionals to make them understand, and make them more aware that ethically, this is not damaging to them as professionals, but it is damaging to your client if they do not?

[...] It is twofold. I would say, one, educate our health professionals as to the importance of getting consent... I do not think they are doing it, and they are not looking at doing it. I think they are sticking to the, “I cannot do it and that is it.” [...] I think we have to open up that door for doctors to say, “Let me look at this. Let me talk with your son, or your daughter, or your mother. Let me try to help this process.” Have doctors say this rather than, “No, I cannot because I am bound by ethics.”¹⁰⁷

Her words were echoed by France Daigle, Suicide Prevention Program, New Brunswick Ministry of Health, who stated that:

The Committee believes that in circumstances where there is clear, serious and imminent danger, health care professionals may have an overriding duty in law to warn third parties and thereby protect the safety of the patient. It does not agree, however, that the role of health care professionals is to act as quasi-judicial arbiters.

...the first thing people say is, “I cannot tell you anything because of confidentiality.” However, when you have someone that is at risk for suicide, and as much as I do respect confidentiality, because we have a code of ethics, what is more important? You have to let the family and other people know.

¹⁰⁷ 11 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*I found that sometimes as caregiver, family members, or professionals, we hide behind this confidentiality. We have to start working together.*¹⁰⁸

The Committee believes that health professionals have an important role to play in improving the flow of information between persons living with mental illness, and their families. Therefore, it recommends:

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| 2 | That health care professionals take an active role in promoting communication between persons living with mental illness and their families. This includes asking persons living with mental illness if they wish to share personal health information with their families, providing them with copies of the necessary consent forms, and assisting them in filling them out. |
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Joan Nazif suggested that the role of health care professionals be expanded still further. She noted that:

*Like many other provinces, we have the Freedom of Information and Protection of Privacy Act, FOIPPA, but unlike some other provinces, we are fortunate to have guidelines for FOIPPA. The guidelines, written by our provincial government Ministry of Health, state that a health provider may decide to share information with family or another third party.*¹⁰⁹

The Committee believes that in circumstances where there is clear, serious and imminent danger, health care professionals may have an overriding duty in law to warn third parties and thereby protect the safety of the patient. It does not agree, however, that the role of health care professionals is to act as quasi-judicial arbiters between persons living with mental illness and their families, or to take the role of privacy commissioners or judges in interpreting legislation governing the right of privacy. Therefore, it recommends:

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| 3 | That health care professionals have discretion to release personal health information, without consent, in circumstances of clear, serious and imminent danger for the purposes of warning third parties and protecting the safety of the patient. That this discretion be governed by a clearly defined legal standard set out in legislation, and subject to review by privacy commissioners and the courts. |
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¹⁰⁸ 11 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁰⁹ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42470-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

4.1.2.3 Substitute Decision Makers and Advance Directives

The Committee was concerned that many families seemed unaware of the fact that provincial laws often anticipate incapacity on the part of persons living with mental illness and contain specific provisions to facilitate the flow of personal health information to them. For example, under Ontario law a mentally capable person may appoint a substitute decision maker and grant him or her the right to access some or all of his/her personal health information. Persons with direct experience of mental illness, like Ron Carten, raised this as an alternative to weakening privacy protections:

*Well, you are questioning whether or not the person who is diagnosed with the mental illness can make a decision. There are such things as advance directives. The Representation Agreement Act of British Columbia provides for those, but explicitly excludes people with mental illness. If that right were granted to people with mental illness, they could appoint someone ahead of time to make decisions for them when they are not capable of doing so.*¹¹⁰

Making advance directives and appointing substitute decision makers would ensure family access to personal health information while also preserving the autonomy and dignity of persons living with mental illness.

Making advance directives and appointing substitute decision makers is a relatively simple process. If it were to be widely employed, it would ensure family access to personal health information while also preserving the autonomy and dignity of persons living with mental illness. For this reason the Committee recommends:

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| 4 | <p>That all provinces and territories empower mentally capable persons, through legislation, to appoint substitute decision makers and to give advance directives regarding access to their personal health information.</p> <p>That provisions in any provincial legislation that have the effect of barring persons from giving advance directives regarding mental health treatment decisions be repealed.</p> <p>That all provinces and territories make available forms and information kits explaining how to appoint substitute decision makers and make advance directives.</p> <p>That all provinces and territories make available community-based legal services to assist individuals in appointing substitute decision makers and making advance directives.</p> |
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¹¹⁰ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42471-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

That all provinces and territories undertake public education campaigns to educate persons with mental illness, and their families, about the right to appoint a substitute decision maker and make an advance directive.

4.1.2.4 Filling the Gap

The Committee is aware that pre-planning will not occur in every case. Individuals may not anticipate becoming ill and therefore may not name a substitute decision maker or make an advance directive. After all, it is not uncommon for people, particularly young people, to die without having given any thought to estate planning, let alone preparing a valid will.

The best we can hope for is to offer Canadians and their families the opportunity to plan for their being incapacitated in the future and, should they fail to do so, offer them a second window of opportunity.

In cases such as these, it is important that some legal mechanism be put in place to fill the gap. It is reasonable to assume that individuals affected by a mental illness would want and expect their spouses, children, parents or other family members to care for them in the same way they would in the case of an unanticipated physical illness. It is also reasonable to expect that those family caregivers would require access to some of the relevant personal health information in order to better care for their sick loved one. Therefore, the Committee recommends:

- 5 **That where a person is diagnosed with a mental illness that results in his/her being found mentally incapable, and where there is no previous history of mental illness or finding of mental incapacity, and where there is no named substitute decision maker or advance directive, the law create a presumption in favour of disclosure of personal health information to the affected person's family caregiver(s).**
- That the provinces and territories enact uniform legislation setting out this presumption.**
- That the legislation specify an "order of precedence" for relatives (i.e., if the person is married, or living in a common-law relationship, disclosure would be to his or her spouse or common-law partner, and if there is no spouse or common-law partner, to the person's children, etc.).**

That the legislation specify the information to be disclosed, including: diagnosis, prognosis, care plan (including treatment options, treatment prescribed, and management of side-effects), level of compliance with the treatment regime, and safety issues (e.g., risk of suicide).

That the legislation specifically bar the release of counselling records.

That the legislation oblige the person disclosing the personal health information to notify the mentally incapable person, in writing, of the information disclosed, and to whom it was disclosed.

The Committee realizes that this is not an ideal solution and that families caring for someone affected by a mental illness are unlikely to be fully satisfied. However, it is not our role to compel persons living with mental illness to make any particular decision.

The best we can hope for is to offer Canadians and their families the opportunity to plan for their being incapacitated in the future and, should they fail to do so, offer them a second window of opportunity. If, however, having regained his or her mental capacity someone elects to preclude his or her loved ones from sharing relevant personal health information from that point on, the Committee respects that the choice is that individual's to make.

4.2 CHARTER OF PATIENTS' RIGHTS

4.2.1 Background

The Committee has struggled long and hard with the issue of how to ensure that health care patients receive the care and support they need. In its earlier report entitled *The Health of Canadians — The Federal Role*, the Committee put forward the idea of adopting a charter of patients' rights "as the means of enforcing maximum waiting time standards."¹¹¹ Although this option was eventually rejected in favour of other less legalistic approaches, the idea did not perish.

The Committee acknowledges the support shown for a patients' charter in its second on-line consultation.

During the public hearings that preceded publication of the Committee's background reports on mental health, mental illness and addiction, a number of witnesses raised in this new context the option of a patients' charter. The Committee also took note of the robust vision articulated by the Champlain District Mental Health Implementation Task Force in Ontario. It argued for a charter that:

¹¹¹ Standing Senate Committee on Social Affairs, Science and Technology. (April 2002) *The Health of Canadians — The Federal Role*, Volume 5, Chapter 2, Section 2.5, p. 60.

...would not be limited to mental health services but would also encompass broader social supports. More precisely, the proposed charter included, for example:

- Mental health services that are safe, secure, evidence-based, timely, culturally appropriate and relevant to the individual's needs;
- Services and supports that encourage the involvement of individuals with mental illness and addiction and are based on the principles of recovery, self-help and independent living and functioning;
- Treatment that is respectful of relevant legislation (Mental Health Act, Canadian Charter of Rights and Freedoms, etc.);
- Respect for privacy and informed choices.¹¹²

4.2.2 Stakeholder Consultations

Given the level of interest in a patients' mental health charter, the Committee opted to canvass the issue more broadly. In the Committee's second on-line consultation, Canadians were asked whether they favoured a legislated "Charter of Consumers' Rights," and for their views on what it should include.

The Committee is uncomfortable with the idea of a separate legal regime for persons living with mental illness.

There was support for adopting a legislated patients' charter, although it was somewhat less popular with family members and service providers than with those living with mental illness.¹¹³ Also, there was support for the inclusion of particular items, such as the right to:

1. mental health/addiction services that are at least of the same quality as other health-related services provided to all Canadians,
2. timely access to mental health/addiction services,
3. mental health/addiction services in [a person's] language of choice and reflecting [their] cultural background,
4. a suitable range of medical and non-medical mental health/addiction services, and,
5. protection from the public expression of views that stigmatize or belittle persons living with mental disorders and/or addiction.¹¹⁴

¹¹² Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 8, Section 8.2.7, pp. 164-165.

¹¹³ Ascentum Incorporated. (June 2005) Report on the Online Consultation by the Standing Senate Committee on Social Affairs, Science and Technology, p. 40.

¹¹⁴ *Ibid.*, p. 38.

Although the results of the second on-line consultation were favourable, the proposed patients' charter was not without its critics. For example, two anonymous participants in wrote:

Just what we need ... another Charter ... a piece of paper will really help! NOT! Rather than making the lawyers richer and niche activist groups who pursue lawsuits for their own enjoyment more popular, perhaps the government should consider funding these services properly. Now that would be a novel idea! —Anonymous

The Federal Government would do well to ensure the current Charter of Rights and Freedoms is enforced rather than developing a second Charter for specific populations. —Anonymous

4.2.3 Roadblocks

While the Committee acknowledges the support shown for a patients' charter in its second on-line consultation, it is mindful of roadblocks to the implementation of such a document. They fall into two general categories.

4.2.3.1 Philosophical Roadblocks

The Committee is uncomfortable with the idea of a separate legal regime for persons living with mental illness. In our view, entrenching rights for a particular segment of the population in a distinct legal instrument places the named group at risk of further alienation and stigmatization. This is particularly true if the proposed patients' charter links obligations or "responsibilities" with the rights it seeks to protect.

The Committee is concerned that a patients' charter may have the unintended consequence of diluting, rather than augmenting, existing enforcement mechanisms.

The *Charter of Adult and Family Rights and Responsibilities*¹¹⁵ serves to illustrate the point. This Charter devotes an entire section to the "responsibility" of maintaining good personal hygiene. It reads as follows:

8. Hygiene

- Pay particular attention to your own hygiene. Poor hygiene is offensive to others
- Bathe, brush you [sic] teeth, and wash your hair regularly
- If this is difficult for you ask for assistance. Perhaps you could make this one of your goals.¹¹⁶

¹¹⁵ The *Charter of Adult and Family Rights and Responsibilities* was prepared by The Adult and Family Rights and Responsibilities Charter Committee of Cranbrook, British Columbia.

¹¹⁶ The Adult and Family Rights and Responsibilities Charter Committee. (May 2003) *Charter of Adult and Family Rights and Responsibilities*, p. 12.

While the Committee does not wish to be overly critical of the efforts of a dedicated group of concerned citizens, it questions the utility of a patients' charter that would link the violation of constitutional rights, such as freedom from arbitrary detention, with the failure to act "responsibly" (e.g., defined as failure to wash one's hair).

The Committee is similarly concerned that a patients' charter may have the unintended consequence of diluting, rather than augmenting, existing enforcement mechanisms. Including a legal right within a patients' charter may result in complaints being diverted to other bodies for decision, away from quasi-judicial or judicial enforcement mechanisms in which uniform legal standards apply.

The *Bill of Client Rights*,¹¹⁷ of the Centre for Addiction and Mental Health (CAMH) in Toronto, is used here for illustrative purposes. This document, which is to be distinguished from *The Charter of Adult and Family Rights and Responsibilities*, is a comprehensive rights-based instrument which in our view has the potential to fulfill its intended mandate to promote "...the dignity and worth of all of the people who use the services of the Centre for Addiction and Mental Health."¹¹⁸ The difficulty, however, is that it strays into the realm of pre-existing legal rights.

Our preferred course of action would be to facilitate access to personal health information in accordance with the procedures and standards set out in existing privacy laws. The suggestion that persons living with mental illness rely on alternative complaint mechanisms makes us uneasy.

Section 6(4) of the *Bill of Client Rights* provides that "every client has the right to view her/his clinical records without undue difficulty."¹¹⁹ It is not clear why this provision is included because in Ontario the *Personal Health Information Protection Act* establishes:

Section 6(4) of the *Bill of Client Rights* provides that "every client has the right to view her/his clinical records without undue difficulty."¹¹⁹ It is not clear why this provision is included because in Ontario the *Personal Health Information Protection Act* establishes:

...a formal process for individuals to access and correct their own personal health information, within specified time frames and the right to complain if an access or correction request is denied.¹²⁰

Complaints are adjudicated by the Information and Privacy Commission of Ontario, which has broad powers to enforce the Act. Also, the Act provides for fines of up to \$250,000 for organizations that commit offences set out in it. The unnecessary duplication puzzles the Committee.

The Committee believes strongly that all Canadians should be afforded equal protection and equal benefit under the law. This includes having their rights spelled out and enforced in a uniform way. Therefore, our preferred course of action would be to facilitate access to personal health information in accordance with the procedures and standards set out in

¹¹⁷ The *Bill of Client Rights* was developed by the clients, families and staff of the Centre for Addiction and Mental Health in Toronto, Ontario, and endorsed by its Board of Trustees.

¹¹⁸ Centre for Addiction and Mental Health. *Bill of Client Rights*.

¹¹⁹ *Ibid.*, Right #6(4), p. 5.

¹²⁰ Information and Privacy Commission of Ontario. Frequently Asked Questions: Personal Health Information Protection Act - What rights do individuals have?
http://www.ipc.on.ca/scripts/index.asp?action=31&P_ID=15371&N_ID=1&U_ID=0&LG_ID=1#individuals.

existing privacy laws. This is why the suggestion that persons living with mental illness rely on alternative complaint mechanisms makes us uneasy.

The Committee appreciates that the *Bill of Client Rights* does not preclude CAMH clients from availing themselves of the enforcement mechanisms set out in the *Personal Health Information Protection Act*. However, we are concerned that those who opt to go this latter route will be viewed as “difficult” or “litigious.” Also, we question whether internal complaint mechanisms, particularly in the absence of third-party adjudication and clearly defined sanctions, will yield equivalent results for complainants.

4.2.3.2 Practical Roadblocks

A number of options for implementing a Charter of Patients’ Rights for mental health services have been suggested. These include creating a Canada Mental Health Act; amending the *Canadian Human Rights Act*; and creating a separate piece of rights legislation to be enacted by Parliament and the provincial and territorial legislatures.

4.2.3.3 Canada Mental Health Act

One possibility would be to establish a federal Mental Health Act setting out the rights of persons living with mental illness with respect to mental health services. However, there are a number of significant difficulties associated with such a proposal.

The primary barrier relates to the division of powers in the Canadian constitution. With some exceptions, provinces generally have jurisdiction over health, including over hospitals, the direct delivery of most medical services, the education of physicians, and other related functions.¹²¹ Mental health services are primarily under provincial jurisdiction.

Under the Canada Health Transfer (CHT), the federal spending power is used to influence the Canadian medicare system.¹²² The same power is also used to set national standards through the *Canada Health Act*, the purpose of which is “to establish criteria and conditions in respect of insured health services and extended health care services provided under provincial law that must be met before a full cash contribution can be made.”¹²³ The *Canada Health Act* allows the amount of money to be transferred under the CHT to be reduced in two ways: one, if a province allows extra-billing¹²⁴ or user charges¹²⁵ and two, if the health insurance plan does not satisfy the criteria of public administration, comprehensiveness, universality, and portability.

¹²¹ Young, M. (December 2000) *The Federal Role in Health and Health Care*. TIPS-59E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, p. 1.

¹²² *Ibid.*, p. 2.

¹²³ *Canada Health Act*, c. 6, s. 4.

¹²⁴ “Extra-billing” is defined in the *Canada Health Act* as “the billing for an insured health service rendered to an insured person by a medical practitioner or a dentist in an amount in addition to any amount paid or to be paid for that service by the health care insurance plan of a province.”

¹²⁵ “User charge” is defined in the *Canada Health Act* as “any charge for an insured health service that is authorized or permitted by a provincial health care insurance plan that is not payable, directly or indirectly, by a provincial health care insurance plan, but does not include any charge imposed by extra-billing.”

At the same time, it is important to note that the *Canada Health Act* does not cover services provided in a hospital or institution primarily for people with mental illness. This was pointed out by Dr. Sunil Patel, then president of the Canadian Medical Association, when he appeared before the Committee. He suggested that the *Canada Health Act* be amended to include such psychiatric services.¹²⁶

The Committee believes, however, that such an amendment would be largely symbolic for two reasons: first, most stand-alone psychiatric institutions have been closed in favour of providing mental health services in the same hospitals in which physical health services are provided; and second, many services essential to persons living with mental illness (i.e., psychological services or drug therapies) have no or limited coverage under existing provincial health plans. Hence, the Committee does not favour such an amendment to the *Canada Health Act*.

It might nonetheless be possible to develop a Canada Mental Health Act along the lines of the *Canada Health Act*, that is, to tie federal transfers to provincial/territorial compliance with certain principles that guide the provision of mental health services. However, it is difficult to envision how such a law would be enforced, notably because transfers to the provinces are not divided into separate “physical health” and “mental health” categories.

As well, a number of criticisms have been raised with respect to the *Canada Health Act* that illustrate some of the problems that would likely apply to a Canada Mental Health Act. In 2002, the Auditor General pointed out that Health Canada still did not have adequate information to assess the extent of provincial and territorial compliance with the *Canada Health Act* criteria and conditions.¹²⁷ The Auditor General was also troubled by the length of time it was taking to resolve compliance issues:

Health Canada has tended to take a non-intrusive approach to administering the Act. However, this approach has not brought about the speedy resolution of issues related to non-compliance with and interpretation of the Act. The majority of the non-compliance issues identified by Health Canada over the past 10 years have remained unresolved for five years or longer.¹²⁸

Furthermore, it is important to recognize that the penalties that have actually been enforced under the *Canada Health Act* relate to user fees and extra-billing; the deduction for non-compliance with the criteria or conditions of the Act has never been used. Given that matters relating to mental health care services

The potential barriers and concerns outlined suggest that a *Canada Health Act* model would make it a less-than-ideal vehicle for a Charter of Patients' Rights.

¹²⁶ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 3, Section 3.4.1, p. 58.

¹²⁷ Report of the Auditor General of Canada — September 2002, Chapter 3, “Health Canada — Federal Support of Health Care Delivery,” paragraph 3.2.

¹²⁸ *Ibid.*, paragraph 3.76.

would likely fall under the same broad criteria of “comprehensiveness” and “universality” that apply under the *Canada Health Act*, past practice suggests that if a model similar to the *Canada Health Act* were created, effective enforcement would probably not take place.

The potential barriers and concerns outlined above suggest that a *Canada Health Act* model would make it a less-than-ideal vehicle for a Charter of Patients’ Rights.

4.2.3.4 Amending the Canadian Human Rights Act

Another option to implement a Charter of Patients’ Rights would be to amend the *Canadian Human Rights Act*. As described in section 2 of the *Canadian Human Rights Act*, its purpose is to:

extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament, to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted.¹²⁹

The *Canadian Human Rights Act* applies only to areas of federal jurisdiction. Therefore it would not be a useful instrument through which to require amendment of provincial mental health legislation or improve services to persons living with mental illness.

Some of the activities prohibited by the Act include:

- denying access to goods, services, facilities, or accommodations on a prohibited ground of discrimination (s. 5);
- refusing to employ or refusing to continue to employ an individual on a prohibited ground of discrimination (s. 7);
- publishing or displaying a notice or sign that expresses or implies discrimination or incites others to discriminate (s. 12); and
- telecommunicating hate messages (s. 13).

The *Canadian Human Rights Act* applies only to areas of federal jurisdiction. Therefore it would not be a useful instrument through which to require amendment of provincial mental health legislation or improve services to persons living with mental illness. The Act applies, however, to the provision of health services to First Nations and Inuit, veterans and federal offenders — populations that have certain health services provided to them by the federal government.

¹²⁹ R.S. 1985, c. H-6, s. 2.

Other than requiring that federally regulated service providers avoid discrimination in the provision of services, there is nothing in the *Human Rights Act* that outlines how specific services are to be provided. It may be possible to amend the Act to include specific references to the provision of services. However, such an amendment would have limited application, given that it would apply only to specific populations and in specified circumstances.

4.2.3.5 Creating a Separate Piece of Legislation to be Enacted by Parliament and the Provincial and Territorial Legislatures

Given the provincial jurisdiction over health (with the exception of legislation that sets out rights to mental health and other services for populations over which the federal government has responsibility), any legislation enacted by Parliament would likely be limited to making financial transfers to the provinces contingent on their meeting certain criteria, in a similar fashion to the way that the *Canada Health Act* operates.

Developing model uniform legislation that could be adopted by the provinces and territories would appear to be the option with the greatest chance of leading to the creation of a charter of rights for people living with mental illness. However, given the Committee's objections to a separate legal regime for mental health, this is not a course of action it is prepared to recommend.

The federal government could, however, invite the provinces and territories to participate in a process to review existing mental health legislation. The goal of the review process would be to develop framework legislation that sets out specific rights to mental health services that could be adopted by the provinces and territories and by the federal government with respect to the populations under its jurisdiction. Such a federal/provincial/territorial review of legislation could take place as part of the Annual Conference of the Federal/Provincial/Territorial Ministers of Health.

Alternatively, it may also be possible to recommend that the Uniform Law Conference of Canada develop model legislation that would set out uniform consumers' rights to mental health services. In 1987, this Conference endorsed a Uniform Mental Health Act developed to ensure that provincial legislation did not violate the *Charter of Rights and Freedoms*.

The Uniform Law Conference has a criminal law group and a civil law group, and was founded to harmonize the laws of provinces. Government policy lawyers and analysts, private lawyers and law reformers gather on a regular basis to consider areas of provincial and territorial law that would benefit from harmonization.¹³⁰ Once an area has been studied and draft legislation has been developed, the civil law group adopts the draft legislation and recommends that it be enacted by all relevant governments in Canada.¹³¹

As mentioned above, it is virtually certain that any attempt by Parliament to establish legislation setting out the rights of persons living with mental illness to mental health services would be rejected by the provinces and territories. The option of making transfer payments contingent on meeting criteria for mental health services is problematic, as

¹³⁰ Uniform Law Conference Web site, <http://www.chlc.ca/en/civil>.

¹³¹ *Ibid.*

described earlier for the *Canada Health Act*. Developing model uniform legislation that could be adopted by the provinces and territories would appear to be the option with the greatest chance of leading to the creation of a charter of rights for people living with mental illness. However, given the Committee's objections to a separate legal regime for mental health, this is not a course of action it is prepared to recommend.

4.3 THE MENTAL DISORDER PROVISIONS OF THE *CRIMINAL CODE*

4.3.1 Background

Part XX.1 of the *Criminal Code* sets out a comprehensive and independent regime governing accused persons who are found either unfit to stand trial or not criminally responsible for an offence on account of mental disorder. Although it was not our intention, the Committee has found itself drawn into the recent debate surrounding this regime. Given its very recent review and amendment by Parliament, our comments will be limited to those issues that were not resolved by the passage of Bill C-10.¹³²

4.3.2 Power of Review Boards to Order Assessments

Review Boards have two primary functions. First, when an accused person has been found by a court to be unfit to stand trial:

...the disposition may initially only be a conditional discharge or hospital detention, not an absolute discharge. At each hearing to review the disposition, the Review Board is to determine whether the accused has become fit to stand trial and if so, send him or her back to court. If the court concludes that the accused is indeed fit, a trial may proceed. If the accused is found to remain unfit, he or she will remain subject to further Review Board hearings.¹³³

Review Boards may also recommend that a court hold an inquiry where a person poses no significant threat to the public and is unlikely ever to become fit to stand trial. Such an inquiry may result in a stay of proceedings.

Information needed by Board members to make appropriate dispositions is not always available.

Second, if a court finds an accused person not criminally responsible on account of mental disorder:

...it may choose one of three dispositions: an absolute discharge, a conditional discharge...or detention in hospital... Alternatively, and very frequently, the court refers the decision to the Review Board of the appropriate province or territory. Any disposition other than an absolute discharge must be reviewed annually by the Review Board

¹³² An Act to amend the Criminal Code (mental disorder) and to make Consequential Amendments to Other Acts, S.C. 2005, c. 22.

¹³³ Raaflaub, W. (June 2005) The Mental Disorder Provisions of the Criminal Code. PRB 05-05E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, p. 5.

until it determines that the accused is not a significant threat to the safety of the public and discharges him or her absolutely.¹³⁴

In all cases, the law requires that Review Boards impose the least restrictive disposition necessary. However, the Committee was alerted to the fact that information needed by Board members to make appropriate dispositions is not always available. Judge Schneider, Alternate Chair of the Ontario Review Board and the Nunavut Review Board, testified that:

...the courts rarely, upon a verdict of either unfit to stand trial or not criminally responsible, make an initial disposition and leave it to the review boards. To leave the review board in a position where it does not have, in the spirit of Winko, the full ability to order assessments is really inconsistent with the reasoning of the Supreme Court.

(...) the fact that somebody had been seen and an opinion offered with respect to fitness over the last 12 months is really next to irrelevant because fitness is something that fluctuates as a function of the individual's clinical condition; it can change day-to-day, hour-to-hour. So, to limit the board's ability to order assessments in the way that it has been done in C-10 I think is unnecessarily restrictive.
—Judge Schneider

Just to put this into perspective, it was obviously written by someone who did not understand how the system worked. There is often a report available that has been produced within the last 12 months. The question is whether it is directed to the issues that we have to decide as a review board.

[...]The reports that would have been prepared and attached to the information or indictment would have gone to the issue of fitness to stand trial or criminal responsibility. They would not have gone to the issue of least onerous, least restrictive disposition, which is what the board has to decide.¹³⁵

Following the adoption of Bill C-10, Review Boards may now order assessments where no assessment report is available or no assessment has been conducted in the last 12 months.¹³⁶ However, as Judge Schneider noted:

The Committee is persuaded by the arguments for the need to increase the powers of Review Boards.

Particularly with respect to the unfits, the fact that somebody had been seen and an opinion offered with respect to fitness over the last 12 months is really next to irrelevant because fitness is something that fluctuates as a function of the individual's clinical condition; it can change day-to-day, hour-to-hour. So, to limit the board's ability to order assessments in the way that it has been done in C-10 I think is unnecessarily restrictive.

¹³⁴ *Ibid.*

¹³⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹³⁶ An Act to amend the Criminal Code (mental disorder) and to make Consequential Amendments to Other Acts, S.C. 2005, c. 22, s. 3.

I would have simply altered the wording in 672.11 and put in beside “court,” “or review board”. It would have been the simplest way around it.¹³⁷

Courts have authority to order assessments at any stage of the proceedings against the accused. The Committee is persuaded by the arguments for the need to increase the powers of Review Boards, and therefore recommends:

-
- | | |
|---|--|
| 6 | That the <i>Criminal Code</i> be amended to grant Review Boards the same powers to order mental health assessments as those it currently confers on courts. |
|---|--|

4.3.3 Power of Review Boards to Order Treatment

Review Boards have no authority to order a mentally disordered accused to undergo treatment. Courts, on the other hand, are empowered to do so by the *Criminal Code* in very limited circumstances. In his testimony before the Committee, Judge Schneider argued that:

Review Boards have no authority to order a mentally disordered accused to undergo treatment. Courts, on the other hand, are empowered to do so by the *Criminal Code* in very limited circumstances.

The biggest one that was missed in C-10 though, quite apart from the ability to make assessment orders, was the ability of the board to treat accused who come through the system as unfit. Now, we do this quite aggressively in the Mental Health Court because we have got practitioners who are very familiar with the legislation and comfortable in applying it, but if you go outside of this little area here, you will find that treatment orders are generally not made by the court, which means that the accused goes to the provincial or territorial review board as unfit and stays within the jurisdiction of the provincial or territorial review board until they are fit.

When the board does not have the ability to order treatment, the same way that the court would have under 672.58, that means that the province or territory where the accused is housed has to rely on whatever the local civil legislation is in order to get them treated. This means that you are going to have somebody unfit staying in the system three, four, five times as long as they would have had the board had just been able to order that they be treated for a period of up to 60 days the same way the courts can under .58.

¹³⁷ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*If the board — which you will remember is made up of a panel of experts — had the same powers as the courts under .58, you would see the unfit people staying in the system for much shorter periods of time. We strongly advocated for that and it just did not receive a mention.*¹³⁸

The issue of involuntary treatment is highly contentious. The Committee heard from many people living with mental illness who strongly oppose forced psychiatric intervention. Their message was unequivocal — imposed treatment is highly damaging to the autonomy and dignity of affected persons:

The Committee heard from many people living with mental illness who strongly oppose forced psychiatric intervention.

In addition to criminal abuse, there is a more consistent abuse of rights of people in the mental health system. It is a constant violation of our right to certain protections under the law.

One example is informed consent. Study after study show that few users are informed about the undesirable effects of the psychoactive medications that are prescribed for them. Least restrictive treatment is frequently violated. The right to refuse treatment has really become often an exercise in evaluating the competency of someone in the mental health system when they dare to refuse the offered treatment. —Jennifer Chambers¹³⁹

If psychiatric treatments were effective and relieved suffering, we would not have the crisis that we have in our health care system. People would love their meds. Forced psychiatry exists because many people often do not feel better, or even loathe the drugs and their damaging side effects.

[...]Just once, treat a patient against her will and if you do not alleviate suffering, you have lost that person's trust and intensified her fears forever. This is a vital issue for virtually all patients and ex-patients I have ever interviewed. Many are terrified of the mental health system. —Rob Wipond¹⁴⁰

The option of electroconvulsive therapy in exchange for an early release forced me to sign the consent form; this is not consent, it is coercion. Many things are “voluntary,” but many things that we consent to are not voluntary. It is just like if you put a gun to my head and make me sign over my property to you,

¹³⁸ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹³⁹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁴⁰ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

that does not equate to consent and that is virtually what the doctors do to the patients.

[...]

I have been phoned by a psychiatrist at my home and been told that I would do what he said, which was to add another pill to my drug cocktail, which at that time was up to four different medications in substantial doses. He told me that if I did not comply he would “send the police to drag me to the hospital in handcuffs.” Those were his words. I was perfectly well at that time. —Francesca Allan¹⁴¹

I would like to share with you at this point the following quote from the director of the World Health Organization who officially declared a global emergency in human rights and mental health, including this very revealing statement: “A human rights violation is not just a matter of denied access to treatment but also and often consists in treatment itself...” This is something for you to reflect upon. My point in all of this is that we are too prone, we are too much in a rush with the most expensive solutions instead of listening to what people really need. It should not be rocket science, but we make it for some reason. —Eugene LeBlanc¹⁴²

...you cannot believe how horrified I was — I read the presentation of the Schizophrenia Society that suggested you actually recommend removing the right of forensic patients to refuse treatment under the Criminal Code. —Randy Pritchard¹⁴³

In light of these and other submissions, the Committee has reservations about involuntary treatment although it may be required in very rare circumstances. We recognize that forcing individuals to submit to psychiatric intervention in the absence of their, or their substitute decision makers', consent has real and profound consequences for their autonomy and dignity. Moreover, doing so may violate their *Charter* rights.

Having said that, the powers granted to courts by the *Criminal Code* permit involuntary treatment in very limited circumstances. Treatment dispositions may be made on application by the prosecutor for the sole purpose of making a mentally disordered accused fit to stand trial. Medical evidence must be presented, the disposition is limited to 60 days, and neither

¹⁴¹ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁴² 11 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eve-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁴³ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

psychosurgery nor electroconvulsive therapy may be administered. Further, the accused is entitled to challenge the treatment disposition.

We acknowledge the objections to forced psychiatric intervention made to us by persons living with mental illness, and we respect them. We also recognize, however, that the need to shorten the period of time that individuals found unfit to stand trial stay in the system is pressing and substantial. The following decision was not taken easily or lightly. However, the singular purpose of the treatment disposition, coupled with the short time limit, the prohibition of certain highly invasive therapies, and the existing procedural safeguards, give the Committee substantial comfort. Therefore, we recommend:

We recognize, however, that the need to shorten the period of time that individuals found unfit to stand trial stay in the system is pressing and substantial.

-
- 7 **That the *Criminal Code* be amended to grant Review Boards the same powers to order treatment as those it currently confers on courts.**

4.3.4 Fitness to be Sentenced

Currently, there is a gap in the law pertaining to the issue of fitness to stand trial. This gap arises when a person becomes unfit *after* a verdict has been reached. In other words, the person is not “unfit to stand trial,” but is instead “unfit to be sentenced.” Judge Schneider explained it as follows:

Currently, there is a gap in the law pertaining to the issue of fitness to stand trial. This gap arises when a person becomes unfit *after* a verdict has been reached.

The other major flaw, and I do not think it was addressed in Bill C-10, was altering the definition of “unfit to stand trial” to include the window up to and including the end of sentencing. I think it remains untouched as going to the end of the verdict, which leaves a legal lacuna if the accused happens to post-verdict get unfit prior to being sentenced.

There is a decision by the name of Balliram from Ontario Superior Court, a decision of Justice McWatt, who actually reads in an expanded interpretation of section 2 dealing with “unfit to stand trial”. We were hoping that Parliament would pick up on that in C-10 but they did not.¹⁴⁴

These concerns were echoed by Judge Carruthers, Chair of the Ontario Review Board, who testified that:

¹⁴⁴ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

From a practical point of view, many times a person has decompensated after verdict, pending, say, a dangerous offender application. You are in irons because the person is not qualified or capable of being sentenced, but he has been convicted, and it is crazy to not extend the definition as [Judge Schneider] says from “verdict” to include “sentence,” and then the whole thing is covered.¹⁴⁵

While this issue was not addressed by Bill C-10, it was raised and commented on by the Honourable Irwin Cotler, Minister of Justice and Attorney General of Canada, appearing before the Standing Senate Committee on Legal and Constitutional Affairs to address the proposed legislation. He stated that:

The Committee is concerned that the Criminal Code does not currently provide a way to deal with convicted persons who become unfit to be sentenced after a verdict has been reached.

On the issue of fitness to be sentenced, because reference was made to that, Bill C-10 does not include amendments to provide for a verdict of “unfit to be sentenced” or to provide for assessments at the time of sentencing. This is an important issue on which we felt further research and consultation is needed. Therefore, I share this with your committee as well.

The specific amendments that may be needed here relate as much to the principles of sentencing as they do to the law of governing those with a mental disorder. The Department of Justice has commissioned academic research on this issue that suggests that unfitness at the time of sentence requires a different conceptualization or test for fitness and different consequences from those that would follow from a finding of unfit to stand trial.

While I agree that this issue must be addressed, we have not included specific amendments in Bill C-10 in relation to it. Amendments may be considered for inclusion in a forthcoming criminal law amendment bill following further consideration and consultation with provincial and territorial ministers responsible for justice, to which this has been referred.¹⁴⁶

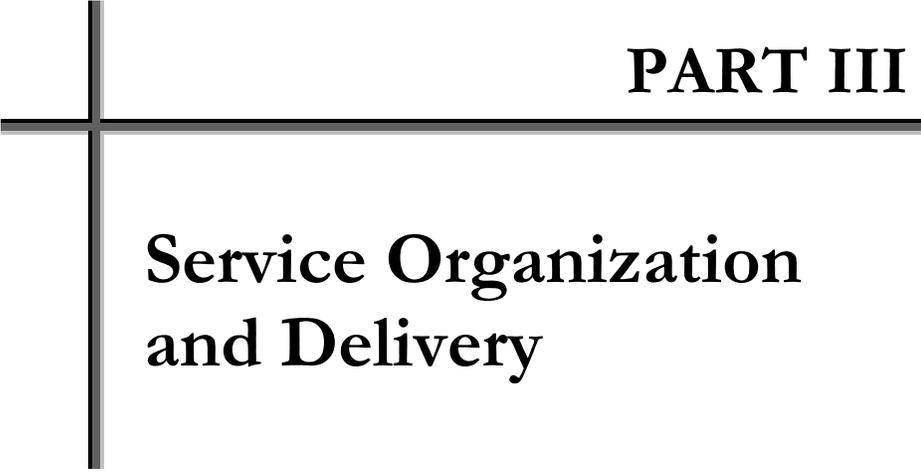
The Committee is concerned that the *Criminal Code* does not currently provide a way to deal with convicted persons who become unfit to be sentenced after a verdict has been reached. However, given the complexity of the issue and the fact that the Government of Canada is currently taking steps to address it, we believe that putting forward a specific proposal at this time would be premature. Instead, we recommend:

¹⁴⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁴⁶ 13 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/lega-e/09eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=11.

8 That the Government of Canada, in consultation with provincial and territorial ministers responsible for justice, develop proposed amendments to the *Criminal Code* to address the issue of convicted persons who become unfit to be sentenced after a verdict has been reached.

That these amendments be brought before Parliament within one year of the tabling of this report in the Senate.



PART III

**Service Organization
and Delivery**

CHAPTER 5:

TOWARD A TRANSFORMED DELIVERY SYSTEM

5.1 CONSENSUS ON THE DIRECTION FOR MENTAL HEALTH REFORM

Chapter 3 of this report described the Committee's underlying vision of how a transformed mental health system should be organized. At the core of this vision is a recovery-oriented, primarily community-based, integrated continuum of care.

At the core of this vision is a recovery-oriented, primarily community-based, integrated continuum of care.

In the course of its hearings, the Committee was pleased to learn that this vision reflects a strong national consensus on the broad outlines of what a transformed mental health system should look like. This consensus of so many of the key “players,” providers and consumers alike, provides a strong springboard from which to pursue transformation of the way in which mental health services and supports are organized and delivered.¹⁴⁷

In some jurisdictions, the goal of establishing a recovery-oriented, community-based, integrated continuum of care that places people living with mental illness at its centre has been in effect for some time. For example, in October 1988, the Government of New Brunswick created a Mental Health Commission with a mandate to reform mental health delivery. The Commission completed its work in 1996, creating a province-wide mental health delivery system inspired by a vision that aligns closely with that the Committee has outlined.

Three key elements must be part of a transformed mental health system: the system must be recovery-oriented and person-centred; it must be predominantly community-based; and it must be integrated across the full continuum of care and across all age groups.

Table 5.1 presents brief excerpts from documents produced during the past few years that demonstrate the pursuit of a similar approach to mental health reform across the country. It contains direct quotes from each report referring to three key elements that must be part of a transformed mental health system: the system must be recovery-oriented and person-

¹⁴⁷ As indicated in Chapter 3, the Committee has not been able to devote as much attention to substance use issues as it intended when it embarked on its study of “mental health, mental illness and addiction.” The Committee recognizes that in previous decades, services for the two types of disorder were administered separately; they developed divergent treatment philosophies, used different terminology and constituted different “cultures” that were often in conflict. However, the limitations of this report with respect to substance use issues means that the Committee has been unable to examine fully the similarities and differences in approach in the mental health and substance use fields. Although some examples are drawn from the substance use sector, the main thrust of this chapter is the transformation of the organization and delivery of mental health services and supports. It would clearly not be appropriate for the Committee to assume that conclusions it has reached after carefully considering the mental health evidence necessarily apply with respect to substance use issues. Some may apply, but the Committee has attempted to avoid any unwarranted assumptions in this regard.

centred; it must be predominantly community-based; and it must be integrated across the full continuum of care and across all age groups. The last row in the Table contains excerpts from a recent British Columbia document that focuses on transforming services to address substance use and addiction problems, highlighting the same three key elements.

The policy consensus set out in Table 5.1 is based on consistent and compelling Canadian and international evidence that increased provision of services and supports in the community is highly beneficial for people living with mental illness. It indicates also that relying primarily on services and supports delivered in the community does not cost more than mental health delivery systems that rely predominantly on institutions for the provision of services. A recent paper produced for the World Health Organization (WHO) noted that “community-based mental health services generally cost the same as the hospital-based services they replace.”¹⁴⁸

Relying primarily on services and supports delivered in the community does not cost more than mental health delivery systems that rely predominantly on institutions for the provision of services.

People living with mental illness can live productive and meaningful lives in the community.

It is now widely recognized that people living with mental illness can live productive and meaningful lives in the community. That is not to say that people with a serious mental illness will not require intermittent periods of institutional care. Rather, it points to the need for policies to be put in place to make certain that the right conditions are in place to support as many people as possible living in their communities.

As Elliot Goldner pointed out in summarizing the results from a number of mental health studies financed by the Health Transition Fund:

Up until recently, hospitalization for psychosis was seen to be the safest route for the patient and society. It was believed to be too risky to try to treat psychotic patients at home. But Home-Based Program for Treatment of Acute Psychosis in Victoria added further weight to previous studies (e.g., Wasylenki, Gehrs, Goering, & Toner, 1997) that showed these patients can be safely managed, stabilized, and returned to a reasonable level of function without the disruption of admission to a psychiatric unit.¹⁴⁹

In fact, many people achieve better outcomes when the proper services and supports are provided in the community. A recent report by the Community Mental Health Evaluation Initiative (CMHEI) in Ontario concluded:

¹⁴⁸ Health Evidence Network, World Health Organization. (August 2003) What are the arguments for community-based mental health care? p. 4.

¹⁴⁹ Goldner, E. (2002) Mental health. Health Transition Fund Synthesis Series, Health Canada, p. 8.

Table 5.1 Excerpts from Provincial Documents

| | | <i>Recovery/person-centred</i> | <i>Community-based</i> | <i>Integrated continuum of care</i> |
|-------|---------------------|--|---|---|
| Nfld. | 2001 ¹⁵⁰ | <p>Person-Centered and Participatory:</p> <ul style="list-style-type: none"> ▪ [the system is] responsive to the unique needs of the individual, across all age groups ▪ individuals and communities define their own needs and participate in the planning and delivery of services | <p>Community-Based [system:]</p> <ul style="list-style-type: none"> ▪ supports the individual living in the community ▪ provides the least restrictive form of care as close to home as possible | <p>A Comprehensive Continuum:</p> <ul style="list-style-type: none"> ▪ provides a continuum of services and supports, including informal supports, focused on well-being and recovery ▪ encompasses promotion, prevention, crisis intervention, acute and continuing care, case management and support... |
| | 2005 ¹⁵¹ | <p>The person/family receiving services must be the central focus of any intervention. Consumer knowledge, expertise and leadership are key components of the mental health and addictions system.</p> | <p>Approaches to be adopted include:</p> <ul style="list-style-type: none"> ▪ Establishment of a range of community-based, best practice, specialized mental health/addiction services in each region that best meets the needs of the population. | <p>The nature of mental illness and addictions often necessitates a comprehensive team approach that involves access to a variety of treatment and support interventions. No one service is usually adequate to meet the diverse needs of this population. Cooperation and collaboration among a range of service providers is essential.</p> |
| Que. | 2005 ¹⁵² | <p>Recovery: the action plan reaffirms the ability of individuals to take control of their lives and play an active role in society.</p> <p>Recovery invites us to support individuals with mental illness by helping them resume their role in society, in spite of their symptoms or handicaps, since social interaction is usually how individuals learn that their efforts give them power over their environment.</p> | <p>The mental health network must offer quality services to the entire population (children, youth, adults, cultural communities, Aboriginals etc.). To support this vision, the measures in the plan focus on establishing front-line services in local communities, utilizing the expertise of local workers. An organization encouraging a smooth transition to specialized services is the basis for this plan.</p> | <p>Continuity: The action plan focuses on the importance of meeting individuals' needs by breaking down the barriers in our work and providing the necessary liaison to limit interruptions in service.</p> |

¹⁵⁰ Government of Newfoundland and Labrador. (September 2001) Valuing mental health: A framework to support the development of a provincial mental health policy for Newfoundland and Labrador.

¹⁵¹ Government of Newfoundland and Labrador. (2005) Working together for mental health: A provincial policy framework for mental health & addictions services in Newfoundland and Labrador.

¹⁵² Quebec, Ministère de la santé et des services sociaux. (2005) Plan d'action en santé mentale 2005-2010 — La force des liens.

| | | <i>Recovery/person-centred</i> | <i>Community-based</i> | <i>Integrated continuum of care</i> |
|------|---------------------|--|---|--|
| Ont. | 1999 ¹⁵³ | The consumer is at the centre of the mental health system; | People with serious mental illness will achieve greater independence; that is, the ability to live in the community with the least intervention from formal services and, to the greatest extent possible, make their own decisions. | Mental health services and supports: <ul style="list-style-type: none"> Are provided within a comprehensive service continuum developed to meet consumer needs and based on best practices. |
| | 2002 ¹⁵⁴ | A critical success factor for implementing mental health reform in Ontario is the philosophy that recovery — as defined by the individual, not by service providers — is possible for all people living with mental illness. With the appropriate treatment and supports in place, people living with mental illness can take charge of their lives, create new goals and aspirations, and engage in society as productive citizens. The Provincial Forum believes the recovery philosophy must be embraced and endorsed as an integral tenet of a reformed mental health system. | A system that creates local systems of care where people living with mental illness, and their families and support networks, can get access to a range of community-based services and supports that are tailored to their needs. Central to the recovery philosophy is the idea that mental health services should be developed within a natural community, not replicated by the mental health system. The community should enable those with mental illness to find gainful employment, participate in supported education programs, and volunteer or participate in society in meaningful ways. | A system that delivers, without fail, a continuum of care — with programs, services and supports available at every stage of life and as close to home as possible. |

¹⁵³ Government of Ontario. (1999) Making it happen: Operational framework for the delivery of mental health services and supports.

¹⁵⁴ Government of Ontario. (December 2002) The time is now: Themes and recommendations for mental health reform in Ontario. Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs.

| | | <i>Recovery/person-centred</i> | <i>Community-based</i> | <i>Integrated continuum of care</i> |
|-------|---------------------|--|--|--|
| Alta. | 2004 ¹⁵⁵ | <p>Clients and their families will come first. The first and primary purpose of mental health services, plans, research and support is to improve the outcomes for people with mental illnesses and their families. That means services must be appropriate to the circumstances of the people served and that they are treated with dignity and respect. ... And most important, it means people with mental illnesses and addictions are able to live productive and positive lives.</p> | <p>All Albertans should have optimal access to the best mental health care options regardless of where they live in the province. The right services will be delivered to the right clients in the most appropriate setting, whether that's in communities, in community hospitals, or in specialized facilities.</p> | <p>Instead of the fragmented system we see today, mental health services will be fully integrated with the health system and the importance of mental health will be recognized and included in the health care system. Care plans will be in place so people with mental illnesses receive seamless care from multiple service providers and supports provided by a range of health care providers, health authorities, community agencies and provincial ministries.</p> |
| BC | 2004 ¹⁵⁶ | <p>The term "client-centred" refers to the unique needs, strengths, motivations and goals of individuals. Client-centred responses "meet people where they are" by removing barriers to access and respecting individual readiness to change. Given the co-morbidity of substance use disorders and mental disorders, client-centred also means providing an integrated and evidence-based system of mental health and addictions care.</p> | <p>Enabling people and groups at the community level to be active participants in, rather than passive targets of, efforts to address problematic substance use is another component of an effective response. Community organizations provide critical support by engaging members of groups most vulnerable to problematic substance use, fostering social inclusion, supporting individuals and families, and by providing a vital bridge for knowledge transfer.</p> | <p>System integration can minimize the fragmentation that allows people to "fall through the cracks". An effective response to concurrent disorders and multiple diagnoses requires a comprehensive, integrated and evidence-based continuum of addictions and health services. These services include health promotion, prevention, harm reduction, early identification, treatment, long-term rehabilitation and relapse prevention, community re-integration and support.</p> |

¹⁵⁵ Government of Alberta. (April 2004) Advancing the mental health agenda: A provincial mental health plan for Alberta.

¹⁵⁶ Every Door is the Right Door: A British Columbia Planning Framework to Address Problematic Substance Use and Addiction. BC Ministry of Health, 2004.

Findings from the CMHEI projects clearly show that community mental health is making a difference in the lives of people with serious mental illness, their families, and caregivers. Data indicate that community-based services and supports can help reduce symptoms and increase the ability of people with serious mental illness to live in the community, rather than in hospitals and institutions. Many clients are showing improvement in their daily lives, community functioning, symptoms, and abuse of substances. They also are experiencing fewer crisis episodes and days in hospital.¹⁵⁷

While the Committee believes that a transformed system must be predominantly based in the community, institutional services also constitute an essential component of the continuum of care. It is the over-reliance on certain kinds of institutional services that has long been the problem. What is required is the right blend of institutional and community-based supports and services. In this regard, the Committee agrees with the approach presented in the paper produced for the WHO cited above:

While a transformed system must be predominantly based in the community, institutional services also constitute an essential component of the continuum of care. It is the over-reliance on certain kinds of institutional services that has long been the problem.

In the last two decades, there has been a debate between those who favour providing mental health treatment and care in hospitals, and those who prefer providing it in community settings, primarily or even exclusively. A third alternative is to utilize both community services and hospital care. In this balanced care model, the focus is on providing services in normal community settings close to the population served, while hospital stays are as brief as possible, promptly arranged and used only when necessary. This balanced interpretation of community-based services goes beyond the rhetoric about whether hospital care or community care is better, and instead encourages consideration of what blend of approaches is best suited to a particular area at a particular time.¹⁵⁸

Many of the services that people need to live successfully in their communities may well emanate from institutions such as hospitals. The key issue is to ensure that those services are accessible in the community and that the people who need them are not admitted unnecessarily as in-patients. Community-based services must be accessible, appropriate, in the right place at the right time, and the least restrictive possible while, of course, achieving good clinical outcomes. Many hospitals run excellent community-based programs that meet these criteria.

Community-based services must be accessible, appropriate, in the right place at the right time, and the least restrictive possible while, of course, achieving good clinical outcomes. Many hospitals run excellent community-based programs that meet these criteria.

¹⁵⁷ Community Mental Health Evaluation Initiative (CMHEI). (October 2004) Making a difference: Ontario's community mental health evaluation initiative, p. 43.

¹⁵⁸ Health Evidence Network, World Health Organization. (August 2003) What are the arguments for community-based mental health care? p. 5.

Moreover, it is important to ensure that as many service providers and stakeholders as possible join together in a common purpose. While in-patient resources must be valued and continue to be available, the reform process should result in the reorientation of all services to support community living and the avoidance of hospitalization.

5.2 SOME ADVANTAGES OF COMMUNITY-BASED SERVICES

5.2.1 Many Community-Based Services can Save Money

As already noted, the evidence suggests that “community-based models of care have been shown to be largely equivalent in cost to the services they replace, so they cannot be considered primarily to be cost-saving or cost-containing measures.”¹⁵⁹ On the other hand, a community-based system need not be more expensive than an institutional one. In fact, there are many specific services and supports that can be provided more cheaply in the community than in hospital.¹⁶⁰

Consider the following example.¹⁶¹ Five years ago, a high-support housing program opened its doors to 30 of Ontario’s most severely disabled people. The residents ranged in age from 41 to 69 and had been ill, on average, for 27 years. They all had a serious mental illness as well as other serious medical conditions:

- 9 had diabetes;
- 8 had a history of substance use problems;
- 6 were developmentally delayed;
- 6 had been ordered into treatment by the Ontario Review Board;
- 5 had serious arthritis;
- 3 had chronic obstructive pulmonary disease;
- 3 had seizure disorders;
- 1 had cancer.

Previously, all had been long-term in-patients in provincial psychiatric hospitals; many of them, despite repeated attempts, had been unable to manage in non-hospital, non-institutional accommodation.

¹⁵⁹ *Ibid.*, p. 15.

¹⁶⁰ Ontario Federation of Community Mental Health and Addiction Programs. (2003) Outcomes and effectiveness: The success of community mental health and addiction programs, pp. 8-9.

¹⁶¹ Ontario Federation of Community Mental Health and Addiction Programs. (2004) The benefits of funding addiction and mental health services, pp. 7-8.

In the housing unit, the program itself provided the support services that the residents required to cope with their mental illness. Another service provider took care of the residents' medical needs.

Despite the severity of their conditions, these residents have fared remarkably well since entering the program. They have developed a sense of community; they support each other and achieve goals that they could not have previously.

The residents have spent very little time in hospital, saving the health care system an estimated \$4,400,000 annually (or \$146,000 per resident). This estimate was derived from the number of days each resident would have spent in hospital had he or she not moved to the residence, multiplied by the hospital per diem, minus the current cost of the person's residential program.

The cost saving illustrated in this example is by no means unique. In Ontario, for example, the 3,130 clients who received Assertive Community Treatment (ACT) services in 2003-2004 spent 26 days in hospital compared with an average of 77 days in the previous year, a reduction of 87%. In 2003-2004, 66% of ACT clients in Ontario were not admitted to a hospital. It is estimated that ACT achieved a cost avoidance of \$82 million in 2002-2003 and \$77.6 million in 2003-2004.¹⁶²

In addition:

- Steve Lurie, Executive Director, Canadian Mental Health Association (CMHA) Metro Toronto, has demonstrated a decrease in total hospitalization costs from \$1,358,136 to \$172,692 for 56 people receiving comprehensive case management services;
- Wendy Czarny, reports an 89% reduction in the average amount of time residents spend in hospital after enrolling in the supportive housing programs of the Waterloo Regional Homes for Mental Health.¹⁶³

The same types of savings are also achieved in programs that focus on the treatment of substance use disorders based in the community. For example:¹⁶⁴

- 89% of people with a substance use problem who were treated in a community-based withdrawal management service showed continued positive outcomes six months after treatment in terms of significantly reduced substance use and improvements in self-esteem and self-confidence;
- Without community-based withdrawal management services, 5% of potential clients are likely to be in jail and 11% in hospital;

¹⁶² Ontario Ministry of Health. 2003/4 ACT data outcome monitoring report.

¹⁶³ Examples drawn from: Ontario Federation of Community Mental Health and Addiction Programs. (2003) Outcomes and effectiveness: The success of community mental health and addiction programs, pp. 9 and 12.

¹⁶⁴ *Ibid.*, p. 9.

- Each dollar spent on community-based treatment of alcohol use disorders saves between \$4.00 and \$12.00 in long-term societal, economic and medical costs;
- The scarcity of withdrawal management services in the community forces many people to turn to hospital emergency rooms for service. Indeed, research suggests that, by a very conservative estimate, alcohol-related problems account for between 10% and 30% of all emergency room visits.

5.2.2 Other Advantages to Basing Services in the Community

It is clearly easier in a community-based system to incorporate community input and to adapt the system to community needs and values than in a system that is institutionally based. Locating services and supports as much as possible in the community also makes it easier to hold those who are responsible for organizing and delivering them accountable to the community itself.

The Committee believes that these features of community-based systems are of particular importance in ensuring that the care, services and supports that are available to Canada's Aboriginal peoples are fully adapted to their traditions. Moving towards a community-based system thus opens the door for Aboriginal communities to be fully involved in the design and implementation of the mental health programs they require to meet their needs.¹⁶⁵

Locating services and supports as much as possible in the community also makes it easier to hold those who are responsible for organizing and delivering them accountable to the community itself.

Moving towards a community-based system thus opens the door for Aboriginal communities to be fully involved in the design and implementation of the mental health programs they require to meet their needs.

Moreover, community-based services offer many additional opportunities to integrate those services and supports in a way that puts the consumer at their centre. It becomes easier to avoid the creation of "silos" by making the delivery of community-based services the focus, regardless of the source of their funding.

Finally, basing services in the community allows volunteers and family members to play a larger role in their organization and delivery; this can both help to expand the range of services and supports that are available to people living with a mental illness, and gear them as much as possible to fostering recovery.

Basing services in the community allows volunteers and family members to play a larger role in their organization and delivery.

5.3 AN INTEGRATED CONTINUUM OF CARE

Before making specific recommendations on how to put in place an integrated continuum of care that is primarily community-based, it is necessary to look more closely at what such a

¹⁶⁵ See Chapters 13 and 14 for an extensive discussion of issues relating to the mental health and well-being of people of Aboriginal origin in Canada.

system would look like. The final report of the Provincial Forum of Mental Health Implementation Task Force Chairs in Ontario contained a succinct description of the difference an integrated continuum of care would make in the lives of people living with mental illness. It deserves to be cited in full:

What will be different

Individuals with a psychiatric disability live in integrated housing that they have selected in their community; work in jobs and/or participate in meaningful activities that they have chosen; have positive relationships with their families; and have friends who rely on them for support and on whom they can rely.

Individuals have services and supports available that they have had a central role in developing, selecting among, and evaluating. These services and supports are focused on supporting people in their recovery processes in their local communities, and are delivered as close to home as and in the least intrusive way possible.

Individuals have access to a comprehensive, well-integrated and balanced range of community, ambulatory and inpatient services and supports, offered by both professionals and peers.

Services and supports are offered in the context of and are responsive to people's economic, cultural and social situations, are based on the latest relevant knowledge and are oriented toward successful coping, empowerment, self-direction and recovery.

Efforts to change negative public attitudes and their resulting behaviours, such as discrimination, are in place in local communities and are working. Local community resources and the responsibility to include all citizens in community life are seen as an integral part of the community framework for support.

Users of services have the resources and authority to hold service providers and funders accountable for the quality of mental health treatment, services and supports they receive.

Individuals with a psychiatric disability are not defined by their disability or illness, are recognized for their strengths and are empowered and have the resources to define and live the lives they want to lead to the absolute best of their ability.

Source: Government of Ontario. (December 2002) *The time is now: Themes and recommendations for mental health reform in Ontario*. Final report of the Provincial Forum of Mental Health Implementation Task Force Chairs.

The key types of services that are required to make such a system a reality are presented in graphic form in the diagram "The Continuum of Care." This diagram is drawn from one of

the Ontario Mental Health Implementation Task Force reports (Toronto-Peel Implementation Task Force Report).¹⁶⁶

This framework does not present a definitive listing and categorization of services and supports; those listed are not exhaustive but are illustrative of the services and supports that are needed. Thus the model should be regarded as one useful way of depicting the range and types of services and supports that are required in a transformed mental health system.

As discussed in Chapter 3, the Committee believes strongly that mental health issues should be approached from a variety of perspectives, only one of which is the “medical” model.

One advantage to this framework is that it is able to encompass the full range of services and supports, listed under three “levels of need” (first-line, intensive and specialized), with a fourth category that cuts across the three levels. This terminology moves away from commonly used terms that some associate with an overtly medical approach, i.e., primary, secondary and tertiary care. As discussed in Chapter 3, the Committee believes strongly that mental health issues should be approached from a variety of perspectives, only one of which is the “medical” model.

Each level of need is associated with a particular array of services and supports. People will usually receive most of their services from within a particular level, but they are not limited only to the services within that level.

First-line refers to prevention, assessment and treatment provided by frontline providers.

a) *First-line*

First-line refers to prevention, assessment and treatment provided by frontline providers, including family physician, primary care clinics, and the providers of mental health services, social services, and hospital emergency services. For most people with mental health problems, the first-line level will be their first contact with mental health services, usually through their family physicians or primary health care teams. When someone’s illness is not too serious or of short duration, the provision of first-line services will usually be enough to meet the person’s needs.

First-line services and supports therefore must be easily accessible to people no matter what their specific needs.

First-line services and supports must be well connected not only to each other, but also to more intensive and “cross-level” mental health services and supports that can be called upon as needed.

First-line services and supports therefore must be easily accessible to people no matter what their specific needs. Providers at this level must to be able to respond to a very wide range of needs, and be extremely sensitive to the confusion, fear, and concern of those experiencing symptoms of mental illness, perhaps for the first time.

¹⁶⁶ These reports build on: Government of Ontario. (1999) Making it happen: Operational framework for the delivery of mental health services and supports.

They need also to be culturally sensitive so that they can respond appropriately to the needs of people from a diversity of backgrounds.

First-line services and supports must be well connected not only to each other, but also to more intensive and “cross-level” mental health services and supports that can be called upon as needed. Individuals who are diagnosed with serious and ongoing mental illness will usually be referred by first-line service providers to intensive or specialized services for further assistance.

b) *Intensive*

Intensive refers to mental health assessment, treatment and support services that are provided in community or hospital settings for people with serious mental illness. People living with serious mental illness will often require ongoing, long-term support from service providers, but not necessarily daily contact. Intensive services and supports are designed to provide continuous contact and support for people who, without them, would be at risk for repeated or prolonged institutionalization in health care or correctional facilities. The needs of most people living with a serious mental illness should be met by community-based intensive services and supports. People who suffer from acute, severe impairment in personal functioning and are at significant risk, such as someone with a severe post-partum depression, could also require these kinds of intensive services.

Intensive refers to mental health assessment, treatment and support services that are provided in community or hospital settings for people with serious mental illness.

Services at this level address the serious and complex mental disorders most common among the general population.

Services at this level address the serious and complex mental disorders most common among the general population (including concurrent disorders, eating disorders, first episode schizophrenia, and personality disorders). Service integration can be facilitated through intensive case management. Intensive services and supports must be well connected to first-line and “cross-level” services and supports and must be able to access, and be backed up by, specialized services and supports so that together they can address people’s unique and/or particularly complex needs effectively.

THE CONTINUUM OF CARE

First Line Services and Supports

Information and
Referral

Outreach and
Engagement

Initial Assessment and
Care Planning

Crisis
Response

Hospital Emergency
Services

Primary
Care

Intensive Services and Supports

Intensive
Case
Management

Intensive Community
Treatment and
Rehabilitation

Intensive Hospital
Inpatient and Outpatient
Services

Specialized Services and Supports

Assertive Community
Treatment Teams

Specialized Outreach
Services

Regional Forensic
Services

Residential
Treatment

Specialized Inpatient
Services

Housing and
Housing Support
Services

Educational and
Vocational
Support Services

Social-
Recreational
Support Services

Consumer
Community
Development

Family
Community
Development

Cross-Level Services and Supports

c) *Specialized*

Specialized refers to highly specialized mental health programs provided in community or hospital settings that focus on serving people whose serious mental illness is characterized by complex and unstable mental disorders. Only those very few people with serious mental illness who require ongoing, daily contact with service providers will need to access such specialized services and supports. As these services are the most specialized, least available and most expensive resources in the mental health system, they must be reserved for those who truly need them and used only when intensive and cross-level services and supports have failed to work for a given individual.

Specialized refers to highly specialized mental health programs provided in community or hospital settings that focus on serving people whose serious mental illness is characterized by complex and unstable mental disorders.

The following are among those whose problems require that they be addressed at this level:

- elderly people suffering from dementia, psychosis and medical illness,
- people who are developmentally disabled with psychiatric disorders and who often display aggressive behaviours,
- people living with schizophrenia who are chronically psychotic, aggressive or suicidal,
- people with complex, treatment-resistant mood disorders.

Specialized services are not synonymous with long-term, institutionalized care. Rather, treatment, rehabilitation and support services can be provided by multi-disciplinary teams that work in ways to enable many people living with these illnesses to continue to live in the community.

Specialized services are not synonymous with long-term, institutionalized care.

Individuals who use specialized services and supports will not always need this level of care. The need of individuals for the whole range of services and supports must be monitored and reassessed continuously as they progress through the recovery processes and as their needs change.

d) *Cross-level*

Cross-level services and supports is a term used by the Toronto-Peel Implementation Task Force to refer to those services and supports that may be needed regardless of whether someone is being served at

Cross-level services include housing and housing supports, educational and vocational services and supports, drop-ins and other social/recreational supports, as well as consumer and family peer/self-help supports.

the first-line, intensive or specialized level of the mental health system. They include housing and housing supports, educational and vocational services and supports, drop-ins and other social/recreational supports, as well as consumer and family peer/self-help supports. Cross-level services and supports are typically — and most effectively and efficiently — delivered in the community, and are amongst those services and supports most often identified by people living with mental illness and their families as being fundamental to the recovery processes.

5.3.1 The Continuum is Local and Complex

The preceding section described the types of services and supports that must be in place for people living with mental illness to live meaningful and productive lives in the community. In the real world, however, what is available will depend on many factors that are unique to the history and circumstances of each community; each will have its own particular mix of services and supports. These will vary not only from province to province, but from region to region and municipality to municipality.

This inescapable regional variation was noted in the mental health plan issued recently by the Quebec government:

The situation in each particular region, as well as available expertise and experience, may mean that the continuum of mental health services differs from region to region. Services must be tailored to suit local needs. At the same time, it is necessary to ensure that a continuum of basic services (what we have called “required services”) is in place.¹⁶⁷

During its cross-country hearings, the Committee was impressed by testimony that described the integrated provision of community-based services and supports in Brandon, Manitoba. Further investigation by Committee researchers, who visited Brandon during the summer of 2005, confirmed the Committee’s initial impression that Brandon stands out as an example of how hard work and careful planning can yield effective results. But, as noted in Chapter 3, the Brandon experience also illustrates also how efforts to provide an integrated continuum of care are both complex and fundamentally local in nature.

The Committee does not believe it wise to attempt to dictate a uniform model that could be implemented somehow across the country.

...we had to go through a process of shifting the beliefs of patients and staff to one that supported the principle that people could live with mental illness disability in the community...

— Albert Hajes

The Committee does not believe it wise to attempt to dictate a uniform model that could be implemented somehow across the country. It is not even possible (or desirable) to do this on a province-wide basis because the effectiveness and efficiency with which services are delivered depend critically on a number of local particularities, including the history of local institutions and the number and characteristics

¹⁶⁷ Quebec, Ministère de la santé et des services sociaux. (2005) Plan d’action en santé mentale 2005-2010 — La force des liens, p. 72.

of the people who live in each community. The Brandon experience illustrates this critical point. While it cannot serve as a template or uniform model, many valuable lessons can be learned from Brandon's success in integrating mental health services, lessons that can be creatively applied throughout the country.

Southwest Manitoba is largely rural farming country, with Brandon, a city of 45,000, as its major urban centre. Health care in Manitoba is managed through Regional Health Authorities (RHAs). The Brandon RHA serves the city and, in addition, provides referral and other services to the surrounding Assiniboine RHA (112,000 square miles, population 80,000) and to four other RHAs in rural areas to the north and east of Brandon.

For most of the 20th century, mental health services for Brandon and the western portion of Manitoba were delivered from the Brandon Mental Health Centre (BMHC), a large psychiatric institution dating from the early 1900s. Mental health leaders in Brandon started planning in the 1980s to transfer the centralized services in the BMHC to the community. The number of beds in the aging BMHC buildings started to decrease in the 1980s, and the BMHC was closed in stages between 1994 and 1999.

Key principles included recruitment and training of proctor paraprofessional staff to provide close and frequent contact with clients to assist with their independent living.

— **Albert Hajes**

Albert Hajes, Regional Coordinator, Mental Health Program, Brandon Regional Health Authority, described to the Committee how key aspects of this transition were managed.¹⁶⁸ In the first place, attitudes had to change:

A very important point is that with the closure of BMHC we had to go through a process of shifting the beliefs of patients and staff to one that supported the principle that people could live with mental illness disability in the community and have good quality of life including a greater participation and full citizenship. It required a shift in thinking away from the traditional institutional model not just in terms of the staff and the patients, but also in the general community.

As well, Mr. Hajes spoke of the need for advance planning:

A transition of this magnitude was not possible without the development of strong community-based services within the general community to support clients. Considerable work was done prior to the implementation of mental health reform and the transition of services to strengthen the capacity of the service structure and the community to sustain clients.

Mr. Hajes then described some of the measures that were taken:

Key principles included recruitment and training of proctor paraprofessional staff to provide close and frequent contact with clients to assist with their independent living. We worked for the establishment of skill development and

¹⁶⁸ 1 June 2006, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

capacity building for clients to acquire the abilities to function with relative autonomy. We helped our clients to gain access to resources and have greater participation within the community. We established the full spectrum of services that are needed to support clients in a normalized community setting.

Brent White, Program Manager, Residential and Support Services in Brandon, elaborated on the proctor program:

In Brandon, we have developed something we call a “proctor service,” which has been likened to home care service, if you will, for mental health clients. Those individuals provide support services to individuals supporting long-term goals. It involves the client in terms of an empowerment process, engaging them in working towards their goals, which might be living goals, educational goals, vocational, or social goals. We have paid a lot of attention to the provision of supportive social programming as well for people.¹⁶⁹

The proctor program has since been adopted by other regions of Manitoba. In Brandon, the proctors, who are mostly employed part-time, each help approximately 150 clients. Proctors are drawn in approximately equal proportions from health professional or psychology students, from people trying to enter the job market, and from retired people looking for part time work; approximately one-third of proctors are themselves former or current clients of mental health services.

We have paid a lot of attention to the provision of supportive social programming as well for people.

— **Brent White**

...there was the need for formation of strong partnerships with other health and social service agencies, hospital services, physicians as well as police, school divisions, property owners and housing authorities and others. ...

— **Albert Hajes**

Mr. Hajes also stressed the importance of broader community involvement:

Additionally, there was the need for formation of strong partnerships with other health and social service agencies, hospital services, physicians as well as police, school divisions, property owners and housing authorities and others. ... If we were asking community partners to share in responsibility for service to mental health clients, we also needed to provide a backup service to them.

Finally, Mr. Hajes explained how the lack of doctors in Brandon served as a catalyst for innovation:

We have a large generic workforce of community mental health workers that have credentials of psychiatric nursing, psychology and social work. The Brandon Mental Health Centre employed a similar staff that did not include many psychiatrists and physicians.

In fact, truth be told, we went through a period of very lean years. At one point in time, we actually had one psychiatrist who came from Winnipeg two or three

¹⁶⁹ 1 June 2006, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evd-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

days a week to sign the documents, and we had a couple of physicians with some mental health experience. That developed the capability and the capacity of the non-medical workforce to be able to respond to the needs. The competencies of our workforce are significantly better, I believe, than what you would see in most other mental health regions.

Currently, the various programs in Brandon are coordinated by a management team that meets every two weeks. Mental health programs receive approximately 10% of the total funds of the Brandon Regional Health Authority, which has preserved the mental health budget allocation even in years when deficits loomed.

First contact with the system can be through a readily accessible and visible “store front” location centrally located in downtown Brandon, close to public transportation and other services on which mental health clients depend.

First contact with the system can be through a readily accessible and visible “store front” location centrally located in downtown Brandon, close to public transportation and other services on which mental health clients depend. This community-based centre also has close working relationships with several allied services and agencies. One of these is the Brandon Friendship Centre, an Aboriginal peoples’ organization to which people can be referred for traditional culturally appropriate treatments, with funding provided through a services contract with the mental health program.

Intensive Case Managers serve people who are living in the community but need continuing support to manage their daily lives.

There are also programs for people at both ends of the age spectrum.

Intensive Case Managers serve people who are living in the community but need continuing support to manage their daily lives. The Psychosocial Rehab-Residential Services helps them find accommodation in the rental market, where they have access to the proctor service described above. The Westman Crisis Services is a nurse-run, 24/7 telephone response centre that operates a mobile crisis intervention service as well as a crisis stabilization unit that can accommodate up to eight people for approximately five days. Those who need acute in-patient psychiatric care can be referred to the Centre for Adult Psychiatry, a 25-bed acute care psychiatric hospital facility connected to the Brandon Regional Health Centre.

There are also programs for people at both ends of the age spectrum. Mental Health Services for the Elderly serves seniors in their homes, while those elderly clients who need acute in-patient care can be referred to the Centre for Geriatric Psychiatry. The Centre operates a 22-bed acute care psychiatric unit connected to the Brandon Regional Health Centre and manages to return 70% of people who are admitted from their home environments to their homes after discharge. The Brandon Mental Health Program’s Child and Adolescent Treatment Centre (CATC) is located in its own building next to a high school; it also focuses on enabling each young person affected by a mental illness to return to his or her school, family and community.

5.4 COMPLETING THE TRANSITION TO COMMUNITY-BASED SERVICES

Although community-based services are being developed in many regions of the country, such as Brandon, the Committee believes that there is still much to be done to allow people living with mental illness to have access to the services and supports they require to live productively in a community setting. Of those who responded to the Committee's second e-consultation, 80% indicated that the services required by people living with mental illness were not available in their communities.¹⁷⁰

The consequences of not having access to services and supports in the community are that people living with mental illness must rely on institutional services that are generally much more expensive, and often not as beneficial. Nancy Beck, Director, Connections Clubhouse in Halifax, recounted the case of a 72-year-old veteran with schizophrenia:

*[Clyde] requires a couple of hours a week of personal care and a couple of hours to help prepare meals. As a mental health client, he is not able to access home care and against his wishes, the recommendation is that he receives long-term care. We estimate it would cost \$400 a month to honour Clyde's wish and help him remain in an apartment that he has lived in for 15 years.*¹⁷¹

Other witnesses stressed the importance of accessible and appropriate housing not only as the necessary foundation for people living with mental illness to remain in the community, but as a cornerstone of reform of the entire mental health system. In the words of Stephen Ayr, Director of Research, Capital District Health Authority in Halifax:

*The next issue is housing. I need not say anything more than if the issue of housing is not addressed, then it is unlikely that any provincial mental health reform will have an impact on the problem.*¹⁷²

Of those who responded to the Committee's second e-consultation, 80% indicated that the services required by people living with mental illness were not available in their communities. The consequences of not having access to services and supports in the community are that people living with mental illness must rely on institutional services that are generally much more expensive, and often not as beneficial.

Witnesses told the Committee that the money that had been spent previously on providing institutional care was not always transferred to the community. Jocelyn Greene, Executive Director, Stella Burry Community Services in St. John's, spoke of the impact of funding cuts to health care during the 1990s:

In particular, in 1995, the cutbacks from the federal government funding resulted in cutbacks in this province in health care and, in particular, the

¹⁷⁰ Ascentum Incorporated. (2005) Final report on the online consultation by the Standing Senate Committee on Social Affairs, Science and Technology, pp. 28-29.

¹⁷¹ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁷² 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*closure of 97 out of the 127 long-term beds at the Waterford Hospital, which is our provincial psychiatric facility. It is not too strong to say that none of those savings realized from the closure of those beds went back to the community. Wherever they went, they certainly did not come to those of us who work in the community.*¹⁷³

Further evidence of the difficulties confronted by community-based mental health services can be found in a survey of its members conducted by the Ontario Federation of Community Mental Health and Addiction Programs in 2002. It concluded that:

- Since 1992, most of the Federation's 212 member organizations have experienced a net decrease of 20% in provincial funding for core programs, taking into account the increased cost of operations since then.
- Eighty percent of respondents have had to close programs temporarily to cope with fiscal pressures. Twenty-five percent of them have closed programs permanently.
- Almost half of the people who need the services of the Federation's member organizations must wait for 8 weeks or more to access them.
- For a significant number of programs (18%), the waiting time can be a year or longer.¹⁷⁴

The Committee was told that the Ontario government is currently making significant investments in mental health services in the community, as are most other provinces. Over the past two years in Ontario, core budgets for community mental health programs have been increased for the first time in 12 years. Despite these efforts, it is clear that there is still a long way to go. For example, Carrie Hayward, Director, Mental Health and Addictions Branch, Ontario Ministry of Health and Long-Term Care, told the Committee that:

The pattern of use of hospital resources by mental health patients, as revealed by a recent Canadian Institute for Health Information (CIHI) report, suggests that there is still considerable scope for shifting treatment to the community.

*Ontario has 6,750 supportive housing units for people with mental illness or addictions, but the Provincial Forum of Mental Health Implementation Task Forces called for 10,000 more across the province, so continued federal support for affordable and supportive housing is welcomed.*¹⁷⁵

More generally, the pattern of use of hospital resources by mental health patients, as revealed by a recent Canadian Institute for Health Information (CIHI) report, suggests that there is

¹⁷³ 15 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁷⁴ Ontario Federation of Community Mental Health and Addiction Programs. (2003) Outcomes and effectiveness: The success of community mental health and addiction programs, p. 13.

¹⁷⁵ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

still considerable scope for shifting treatment to the community. The report's analysis of inpatient hospitalizations indicates that mental health patients are more likely to be hospitalized for extended periods than any other patient group. According to the report:

While the Mental Health patient group made up the smallest percent of all hospitalizations, at just over 3%, it had the third highest contribution to total number of days (7.4%), and had the highest average length of stay of all patient groups, at 14.0 days, more than double the national average length of stay.¹⁷⁶

And:

In contrast to all patient groups, only 50% of patients in the Mental Health group stayed in hospital for seven days or less. Nearly one-quarter of Mental Health patients stayed in hospital for 19 days or more; almost three times higher than all patient groups combined (7%).¹⁷⁷

According to the Organisation for Economic Co-operation and Development (OECD), acute care inpatients are defined as those patients with an average length of stay in hospital of 18 days or less; those required to stay in hospital for longer than 18 days are classified by the OECD as long-term patients. The nearly one-quarter of mental health patients in acute care hospitals who are there for 19 days or longer are, in fact, long-term care patients who are occupying beds in acute care hospitals. While part of the explanation for longer stays in hospital by mental health patients may relate to the nature of their illnesses, it is nonetheless reasonable to assume that many are being kept in expensive acute care hospital beds because there are no alternatives available in the community.

The nearly one-quarter of mental health patients in acute care hospitals who are there for 19 days or longer are, in fact, long-term care patients who are occupying beds in acute care hospitals.

Many are being kept in expensive acute care hospital beds because there are no alternatives available in the community.

In fact, witnesses told the Committee as much. Roy Muise recounted his experience:

*I remember the time when I was ready to leave hospital and I had nowhere to go because I had no income and I had no money. I spent 13 days in hospital only because I had nowhere to go. It is very difficult, given the gaps in our employment history, first, to get a place to live and, second, to come up with the damage deposit and things like that while we are trying to turn our lives around. So, yes, there needs to be something done in housing, that is for sure.*¹⁷⁸

¹⁷⁶ CIHI. (30 November 2005) Inpatient hospitalizations and average length of stay: Trends in Canada, 2003—2004 and 2004—2005, p. 10.

¹⁷⁷ *Ibid.*, p. 12.

¹⁷⁸ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The use of acute care hospital beds to accommodate mental health patients for an extended period for reasons similar to those that kept Roy Muise — completely unnecessarily — in hospital, represents a serious misallocation of scarce and valuable resources; in all probability, the patients' recovery will likely have been substantially delayed to boot! The Committee believes, unfortunately, that this is precisely what is happening right across the country now.

The use of acute care hospital beds to accommodate mental health patients for an extended period represents a serious misallocation of scarce and valuable resources.

5.5 THE NEED FOR A MENTAL HEALTH TRANSITION FUND

As noted earlier, the evidence suggests that, while the transition to community-based services should not be looked on as a cost-saving measure, it will not cost government any more to fund a predominantly community-based system than it does to run one heavily dependent on the institutional sector. The question then arises as to why governments have not been able to complete the transition to a community-based system, given that it offers so many advantages to people living with mental illness and yet costs no more once the transition is complete. There are a number of reasons to explain the uneven progress that has been made across the country in moving towards an integrated continuum of mental health care based predominantly in the community.

The savings that will eventually accrue from downsizing the institutional sector do not materialize all at once; they accumulate gradually as institutional services are phased out.

The two systems must operate in parallel over a considerable period of time; this too costs money. There is never a guarantee that the money saved by closing a big institution, for example, will find its way back into the mental health sector.

The most important of these relates to the dynamics of transferring existing financing from the institutional to the community-based sector. A recent article on the restructuring of mental health policy in Ontario noted that:

Closing psychiatric hospitals, however, takes political will and seed money to develop an infrastructure of community services on which such closures rely. A circular argument lies at its core: while the funds needed to develop community services are tied up in hospitals, hospitals cannot close in the absence of community programs. Transitional funds must thus be allocated to develop a community infrastructure.¹⁷⁹

There are three points to bear in mind in this regard. First, the savings that will eventually accrue from downsizing the institutional sector do not materialize all at once; they accumulate gradually as institutional services are phased out. The practical problem, therefore, is that there are no immediate savings available from within the mental health

¹⁷⁹ Wiktorowicz, M. (2005). Restructuring mental health policy in Ontario: Deconstructing the evolving welfare state. *Canadian Public Administration*, Vol. 48, No. 3, p. 392.

system to finance the creation of new community-based services. Second, because the phasing out of the old system and the introduction of the new one both take time, the two systems must operate in parallel over a considerable period of time; this too costs money. Third, there is never a guarantee that, over the period of time necessary, the money saved by closing a big institution, for example, will find its way back into the mental health sector.

For these three reasons, the Committee believes that a Mental Health Transition Fund (MHTF) must be established. Such a fund would allow the Government of Canada to make money available to the provinces and territories for investment in services and supports that contribute to the transition toward a community-based, integrated continuum of care for Canadians living with a mental illness. This Fund would be a time-limited investment to cover the costs of the transition and to accelerate the process of developing the community-based system.

The Committee believes that a Mental Health Transition Fund (MHTF) must be established.

This Fund would be a time-limited investment to cover the costs of the transition and to accelerate the process of developing the community-based system.

Once a new “steady state” has been achieved — when the community-based services and supports, integrated along the full continuum of care, are fully in place — the provinces and territories will be able to sustain the new community-based system with the same level of government spending as was devoted to the old system with its heavy reliance on institutional delivery. Thus, any federal funding directed at helping the provinces and territories move in this direction would be a genuine transition fund; it would not constitute an ongoing obligation for the federal government, nor generate increased costs for the provincial and territorial governments.

The Mental Health Transition Fund is unlike many other federal initiatives called “transition funds,” including those such as the Primary Care Transition Fund. Too often, such federal initiatives have resulted in the creation of new programs that must either be supported by new provincial money or disbanded once the federal programs that sparked their creation come to an end. Such initiatives are not truly transitional in that once they are started they place ongoing obligations on provincial and territorial governments to fund them with “new money” on a continuing basis.

It is a genuine transition fund in that it is designed solely to cover the costs associated with the shift from one way of organizing mental health services to another that will cost the same once the transition is complete and the transformed system is up and running.

The Committee has been very careful in crafting its recommendations to ensure that this does not happen in the case of the Mental Health Transition Fund. It is a genuine transition fund in that it is designed solely to cover the costs associated with the shift from one way of organizing mental health services to another that will cost the same once the transition is complete and the transformed system is up and running.

The Transition Fund approach is the most appropriate way for the federal government to invest in what is a provincial responsibility – the delivery of mental health services.

The Transition Fund approach is the most appropriate way for the federal government to invest in what is a provincial responsibility – the delivery of mental health services. Because

the federal government is not responsible for the delivery of mental health services in the provinces and territories, it cannot determine which specific services and supports are most appropriately funded with federal money. That requires a detailed understanding of what is needed, which can come only from doing the job day in and day out. Therefore, the provinces and territories must decide how to allocate the money to be transferred.

This, of course, is nothing new. It is in line with many recently negotiated health-related agreements between the federal and provincial/territorial governments. In fact, since the creation of the Canada Health and Social Transfer in 1995 the provinces have been masters of how they spend federal transfer payments related to health and social affairs.

The need for flexibility in relation to federal funding to assist with the diverse local needs of mental health service providers was highlighted by Bonnie Arnold from the Canadian Mental Health Association of Prince Edward Island, who used the example of home care:

However, home care has a very different interpretation from province to province. We believe that it is critical that the federally transferred funds must be sufficiently flexible that they can be used in the most creative and effective ways to best deliver mental health services to P.E.I. and not be tied to one type of service.¹⁸⁰

It is legitimate, however, for the federal government to expect some form of accountability for its funding, in keeping with its responsibilities to Canadians to properly manage public funds. In this case, the federal government, and Canadians generally, should be assured that the money is: (a) spent on mental health projects; and (b) used to increase the total amount each jurisdiction spends to enhance mental health and treat mental illness.

It is legitimate, however, for the federal government to expect some form of accountability for its funding, in keeping with its responsibilities to Canadians to properly manage public funds.

Moreover, the Committee intends that these funds must not only be incremental to the existing level of provincial or territorial spending. The amount allocated must also take into account the increases in mental health funding that would occur with the overall growth of health care spending in each province and territory. In other words, the new funding must be over and above provincial mental health spending, which should increase at the same rate as the rest of health care spending in the province concerned.

To be sure new federal money will be used for its intended purposes, it must be “ring-fenced” in some fashion.

It is important to clarify two points with respect to the Committee’s insistence on the need for new federal money to be used to supplement provincial or territorial spending. First, the Committee does not specify the new or expanded services in which the provinces and territories should invest. It will be up to each province or territory to allocate the new funding to those particular services it needs most, whether to expand or enhance existing services or to create new ones. Second, if individual provinces and territories are able to save

¹⁸⁰ 16 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

money by enhancing productivity, it is entirely up to them to decide how these productivity savings are best spent.

Many believe that to be sure new federal money will be used for its intended purposes, it must be “ring-fenced” in some fashion. As Christine Davis, President, Canadian Federation of Mental Health Nurses, told the Committee:

When money is given to ministries of health and then to health authorities, health authorities do what is most pressing, and that is to reduce wait lists for hip surgery, knee replacement, cardiac surgery and that kind of thing. If it is not earmarked for mental health, it is not put into mental illness and addictions. Mental illness and addictions are at the bottom of the hierarchy of health care, and people with those problems are seen as less deserving than others. It almost needs to be earmarked for mental health from the get-go.¹⁸¹

Some witnesses were concerned that ring-fencing funding for mental health could set restrictive limits on the total amount of funding that was available. But even these witnesses agreed that, given the pressing needs to accelerate change in the mental health sector, ring-fencing was a good idea.

This type of ring-fencing was used in the initial phase of implementing the National Mental Health Policy in Australia.

This is how Dr. John Service, Chair, Canadian Alliance on Mental Illness and Mental Health, expressed it:

You put it best yesterday, Mr. Chairman, when you said you are between a rock and a hard place with these ringed funds. On the one hand, it can be cherry-picked in tough times. We know that has happened across the country. I have been in the game for 30 years and it has happened many times in my experience. Ringed funds are very vulnerable. They also are in a ghetto by themselves; they accentuate separation. One of the things that ringed funds and targeted funding can do is kick-start change. It can buy change. If it is done right and it is tied into the longer term and structural change that is needed, it can be helpful.¹⁸²

The Committee noted in its report on “Mental Health Policies and Programs in Selected Countries” that this type of ring-fencing was used in the initial phase of implementing the National Mental Health Policy in Australia.¹⁸³ All levels of government in that country made a commitment to some form of budget protection so that new injections of federal funds would not be negated by a concurrent reduction in state and territory funding. Specifically,

¹⁸¹ 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁸² 21 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁸³ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 2 — Mental health, mental illness and addiction: Mental health policies and programs in selected countries, p. 8, <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report2/repintnov04vol2-e.pdf>.

the agreement between governments to protect mental health resources had two components:

- a commitment to maintaining the level of expenditure on mental health services; and
- a commitment to reinvest any resources released from closure or rationalization of services back into mental health programs.

The Committee was told by Mr. Dermot Casey, Assistant Secretary, Health and Priorities and Suicide Prevention, for the Department of Health and Ageing, Government of Australia, that efforts to protect mental health spending had been successful, to the point that they were no longer needed. He said that:

The Canadian Mental Health Commission's expertise on mental health policies and best practices and its arm's-length relationship to government make it better placed than Health Canada to oversee the administration of the Transition Fund.

In fact, one of fears of the federal government 10 years ago was that if we were to give money for mental health, then the states and territories would simply take it and spend it somewhere else. We had an agreement with them that they would maintain their level of funding if the federal government added to the pie. We actually tracked the dollars and the states and territories had to report to a system of monitoring expenditure. We do not need that system now, 10 years later, because governments, realizing how important this is at a jurisdictional level, would not use the money for something else because it has become such a political issue in the communities.¹⁸⁴

Despite these arguments in favour, it does not appear to the Committee that it is possible to develop at this time a system of ring-fencing that would allow for robust accountability down to the local level. In fact, the Committee commissioned research on the viability of ring-fencing funding for mental health at the level of the Regional Health Authority. The study concluded that not only is there a “lack of coordination of mental health information provincially and nationally, there is limited population needs assessment, service profiling or links between health, social services, justice and education along the journey of care.”¹⁸⁵ In short, the health information system available to track spending on health care, including mental health, is inadequate for the purpose.

The Committee believes, nonetheless, that it is possible to establish a set of procedures, overseen by the Canadian Mental Health Commission, that would ensure that Transition Fund money was spent as intended. Disbursement of the fund should be managed by the Canadian Mental Health Commission, the establishment of which was agreed to by all the Ministers of Health (with the exception of Quebec) and officially announced by the federal

¹⁸⁴ *Ibid.*, pp. 7-8.

¹⁸⁵ Pepler, E. (October 2005) An evaluation of service delivery and financial data within Alberta for the purpose of evaluating ‘ring-fence’ protection of mental health funding, p. 17.

Minister of Health on 24 November 2005.¹⁸⁶ The Commission’s expertise on mental health policies and best practices and its arm’s-length relationship to government make it better placed than Health Canada to oversee the administration of the Transition Fund.

The Committee believes that priority should be given to initiatives directed at improving the lives of people living with serious mental illnesses, children and adults alike. Those living with these conditions will benefit most from the delivery of a fully integrated continuum of care. But at the same time, this continuum will make a range of services available in the community that will also assist those living with mild to moderate mental illness.

For example, accessible first-line services are needed as the first point of contact both for those with serious illnesses who will need referrals to intensive and specialized services, and for those who can be cared at the first-line level. Similarly, the development of cross-level services will benefit everyone living with a mental illness, although priority access to such services as supportive housing should clearly be given to people coping with serious illnesses.

The Committee is also particularly concerned that the mental health needs of children be a consistent and strong focus in the development of community-based mental health services and supports.

The Committee is also particularly concerned that the mental health needs of children be a consistent and strong focus in the development of community-based mental health services and supports. As reviewed in greater detail in the next chapter, the needs of children and youth are too often an afterthought, left to the end even in discussions of how to improve the overall mental health system. The Committee believes strongly that this must be rectified.

The Committee recommends:

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| 9 | <p>That the Government of Canada create a Mental Health Transition Fund to accelerate the transition to a system in which the delivery of mental health services and supports is based predominantly in the community.</p> <p>That this Fund be made available to the provinces and territories on a per capita basis, and that the Fund be administered by the Canadian Mental Health Commission that has been agreed to by all Ministers of Health (with the exception of Quebec).</p> <p>That the provinces and territories be eligible to receive funding from the Mental Health Transition Fund for projects that:</p> |
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¹⁸⁶ See Chapter 16, “National Mental Health Initiatives,” for a full discussion of the creation and composition of the Canadian Mental Health Commission.

- **Would not otherwise have been funded; that is, projects that represent an increase in provincial or territorial spending on mental health services over and above existing spending on services and supports, plus an increment equal to the percentage annual increase in overall spending on health; and that**
- **Contribute to the transition toward a system in which the delivery of mental health services and supports is based predominantly in the community.**

That in allocating the resources from the Mental Health Transition Fund priority should be given to people living with serious and persistent mental illness and that a strong focus should be maintained on meeting the mental health needs of children and youth.

5.6 THE COMPONENTS OF THE MENTAL HEALTH TRANSITION FUND

This section discusses some of the key services and supports that would be eligible for funding under the Mental Health Transition Fund (MHTF). The total funding required for these initiatives will be discussed in Chapter 16.

To repeat the Committee’s opinion, the MHTF should have two main components: a Mental Health Housing Initiative (MHHI) that will provide federal funds for the development of new affordable and appropriate housing units as well as for rent supplements to allow people living with a mental illness, who could not otherwise afford to do so, to rent accommodation at market rates; and a Basket of Community Services (BCS) that will assist provinces in providing to people living with mental illness a range of services and supports in the community.

5.6.1 The Mental Health Housing Initiative (MHHI)

It would be hard to overestimate the importance of adequate housing for people living with mental illness, in particular those whose illnesses are serious. The scale of the problem is indicated by studies showing that somewhere between 30% and 40% of homeless people have mental health problems, and that 20-25% are living with concurrent disorders, that is, with both mental health problems and addictions.

Somewhere between 30% and 40% of homeless people have mental health problems, and that 20-25% are living with concurrent disorders, that is, with both mental health problems and addictions.

The Committee heard a consistent story everywhere. Christine Davis, President, Canadian Federation of Mental Health Nurses, put it this way:

*Housing is protection from illness. Housing is protection from the vagaries of mental illness, from the voices, from the fears. The federal government must address the lack of affordable housing.*¹⁸⁷

Finding suitable housing is an ongoing challenge. Carol Solberg, Executive Director, Schizophrenia Society of Saskatchewan, explained to the Committee that:

*Most people on social assistance live in very small homes, which are not always in safe parts of town; they may be dingy and do not promote good mental health. I believe that if a person with good mental health had to live in some of those situations they probably would become ill or, if nothing else, depressed.*¹⁸⁸

Jan House told the Committee of her experience trying to find adequate housing for her daughter in Halifax:

*Physical environment is especially important for those with mental illness; however, because they often have little or no income, they are often forced to live in the worst possible neighbourhoods filled with high crime, drugs and violence. In order to ensure she is living in a safe and positive environment, my daughter has been forced to move three times in one year.*¹⁸⁹

Witnesses noted the impact that reduced federal funding has had on the availability of affordable housing. According to the CMHA, between 1980 and 2000, the number of affordable housing units created by the Government of Canada dropped from 24,000 to 940.¹⁹⁰ Linda Chamberlain, of The Dream Team in Toronto, spoke of the shortage of available housing:

Between 1980 and 2000, the number of affordable housing units created by the Government of Canada dropped from 24,000 to 940.

*That is the whole problem. We do not have enough housing. Most times there is a waiting list of 10 years. Sometimes, some of us have taken five years to get in. That is why [we] need more housing. There is just not enough built.*¹⁹¹

Bonnie Arnold, of the CMHA in Prince Edward Island, recounted the challenges that confront agencies in the wake of reduced government housing subsidies, as they continue to

¹⁸⁷ 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁸⁸ 2 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁸⁹ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁹⁰ Canadian Mental Health Association. (April 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology.

¹⁹¹ 15 February 2005,

strive to assist people living with mental illness to secure adequate housing and the services they need.

*While I am speaking about housing, another concern that has come up at the working group level is the fact that subsidized housing programs that were once supported by the federal government no longer exist. It is true that new money has been made available to assist in building housing, but it is impossible for agencies to be able to make the rents affordable to the tenants, who are often single with low income...*¹⁹²

The Committee was also presented with evidence that programs designed to provide support to people living with mental illness do in fact accomplish this goal. Darrell Burnham, Executive Director, Coast Foundation Society/Coast Mental Health Foundation, told the Committee:

*We serve well over 2,000 people. I want to highlight two categories of services. One is that we provide an array of supported housing. Indeed, we pioneered supported housing for people with mental illness in 1974 and now serve over 544 people in many different forms of housing throughout the Lower Mainland in decent neighbourhoods in the community. We have found that it is not only a cost-effective means, in that it keeps people healthy and out of hospital, but also they blend well into the communities. They are not places that stand out and cause any concern in the neighbourhoods, so supported housing works.*¹⁹³

Suzanne Crawford, Program Manager, LOFT Community Services in Toronto, elaborated on the strengths of the supportive housing model:

Programs designed to provide support to people living with mental illness do in fact accomplish this goal.

Why does supportive housing work? We think it works because we promote recovery and independence. We have heard this over and over. We focus on safety. We focus on the physical space. We focus on the 24-hour hands-on support.

*As I said, we need our psychiatrists. We need our clinicians, but you know what? They come into the home. They are there for an hour and they leave. Who is there for the 24 hours a day? It is the supportive housing, and it is the supportive housing in a very psychosocial model. It offers security. It offers peace of mind. It offers flexibility.*¹⁹⁴

¹⁹² 16 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁹³ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁹⁴ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Phillip Dusfresne of The Dream Team spoke to the Committee from personal experience:

I used to live on the street and now I am a member of The Dream Team which is a project that was created by the boards for Mental Health Services and Housing Services back in 1999. ...

We demonstrate the life-altering benefits of supportive housing by telling our stories to politicians at the various levels of government, social service agencies, service clubs, high school and university students, consumer groups and other institutions. ...

People who live in supportive housing live independently. Each of us is assigned a support worker that we could go to whenever we need help. The support workers could help us get on social assistance. They could help us with résumés if we want to go looking for a job. They could help us with doctor and dentist appointments or day-to-day activities if we are not feeling well, but for the most part, we live independently. We do our own cooking, cleaning, grocery shopping and that. Most of us do not have 24-hour support.¹⁹⁵

The Committee was also told about a variety of innovative projects that are under way across the country, both in the governmental and the non-governmental sectors. Audrey Bean, Co-President of L'Abri en Ville in Montréal, told the Committee:

The Committee was convinced by the testimony it heard that there is need for a major federal investment in housing. More housing units are required; more assistance is needed so that people can afford to rent existing apartments at market rates; and more supportive services are needed so that people can live in the community.

We work with the psychiatric institutions to identify people who would benefit from our particular kind of living arrangement. We deal with two things that are essential to stability for someone with a mental illness. One is permanent housing, a home, a place where they can invite people to, a place that reinforces a sense of identity, and a place from which they can then re-relate to their families.

Then, what we provide is social support, so that we have dinners, people go to one another's houses and we provide that bridge back to the community for a person who has suffered the isolation that those with a mental illness so often suffer.

It is a model that is simple and can be done by any community. We are about ... 100 people, with 30 residents, about 60 or 70 volunteers, and a working board of 20 people. We now have a grant. We had one from Human

¹⁹⁵ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*Resources Development Canada, and now one from the McConnell Foundation, to replicate our model in other communities in Canada.*¹⁹⁶

And David Nelson, Executive Director, CMHA, Saskatchewan Division, told the Committee of

...a positive new initiative in this province that is, I believe, groundbreaking. It is the Saskatchewan Rental Housing Supplement. ... It will assist persons with all types of disability to improve their housing situation, and extends well beyond the stereotypical ramp and washroom modifications generally needed by the physically disabled. It will provide resources to those with mental health problems on a continuing basis to assist with renovations such as larger windows, enhanced security, noise control and housing closer to services. ...

*The supplement is strictly for people who are in the rental market and it will not go to the landlords. It will follow persons when they change homes.*¹⁹⁷

The Committee was convinced by the testimony it heard that there is need for a major federal investment in housing. Moreover, the testimony points to three interconnected dimensions to be taken into account with respect to this investment: more housing units are required; more assistance is needed so that people can afford to rent existing apartments at market rates; and more supportive services are needed so that people can live in the community. All three dimensions must be addressed.

The investment required in new supportive housing and supportive services for people living with mental illness cuts across areas both of federal and provincial/territorial responsibility. The provision of the necessary supportive services is a provincial responsibility. Thus, the Committee believes that federal support for these services and supports should be channelled through the Transition Fund to be administered by the Canadian Mental Health Commission. The Committee recommends:

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| 10 | That services and supports directed at enabling people living with mental illness to be housed in community settings be eligible for funding as part of the Basket of Community Services component of the Mental Health Transition Fund and administered by the Mental Health Commission |
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The Committee believes that the first two interconnected dimensions described above (to build new units and to provide rent supplements) should also be channelled through the Transition Fund. However, in managing the housing portion of that Fund, the Canadian Mental Health Commission should make use of existing structures and bodies at the federal

¹⁹⁶ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

¹⁹⁷ 2 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

level that are already responsible for affordable housing initiatives, such as the Canada Mortgage and Housing Corporation.

The Committee notes that, in March 2005, the federal Minister of Labour and Housing announced that rent supplement programs would henceforth be eligible for funding under the existing Affordable Housing Initiative launched to fund the construction of new affordable housing units. The Committee believes that a similar approach should be used with respect to federal financing of housing initiatives for people living with mental illnesses.

The Committee therefore recommends:

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| 11 | <p>That, as part of the Mental Health Transition Fund, the Government of Canada create a Mental Health Housing Initiative that will provide funds both for the development of new affordable housing units and for rent supplement programs that subsidize people living with mental illness who would otherwise not be able to rent vacant apartments at current market rates.</p> <ul style="list-style-type: none">• That in managing the housing portion of the Mental Health Transition Fund, the Canadian Mental Health Commission should work closely with the Canada Mortgage and Housing Corporation. |
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The recommended size of the Mental Health Housing Initiative is discussed in detail in Chapter 16, along with a financial accounting of other recommendations in this report.

5.6.2 The Basket of Community Services

In addition to housing, many services and supports are needed in order to enable people living with serious mental illness to live safely in their communities. Those described below have all been demonstrated to improve the lives of people living with mental illness by making it possible for them to live productively in the community. They are within the Basket of Community Services that are widely recognized by governments as being at the core of a community-based mental health system:

- *Assertive Community Treatment (ACT)* teams that provide continuous and comprehensive treatment, rehabilitation and support services to people with serious mental illness who have multiple and complex needs that cannot be met with less intensive levels of support.
- *Crisis Intervention* units that provide accessible and mobile crisis response services and supports, 24 hours a day and 7 days a week, to clients of all ages.

In addition to housing, many services and supports are needed in order to enable people living with serious mental illness to live safely in their communities.

- *Intensive Case Management* that enables people to meet their treatment, support and recovery objectives, maintain positive change, and live as independently as possible in the community.

It is the particular circumstances of each community that should determine the content of the basket of services that will be most effective.

The Committee is aware that these three by no means constitute all the services that should be eligible for funding under the Mental Health Transition Fund. Many others, such as early psychosis services, services for people with mental illness involved with the justice system, consumer drop-ins, peer support, employment support programs, concurrent disorder programs, services aimed at the mental health needs of refugees and immigrants, could be funded through the Basket of Community Services. But, as we have already noted, it is the particular circumstances of each community that should determine the content of the basket of services that will be most effective. Therefore, the recommendation below is not intended to be prescriptive; it recognizes explicitly the need for local flexibility, subject only to the condition that the services be community-based.

The Committee recommends:

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| 12 | <p>That a Basket of Community Services that have demonstrated their value in enabling people living with mental illness, in particular those living with serious and persistent illnesses, to live meaningful and productive lives in the community be eligible for funding through the Mental Health Transition Fund.</p> <p>That this Basket of Community Services include, but not be limited to, such things as Assertive Community Treatment (ACT) Teams, Crisis Intervention Units and Intensive Case Management programs, and that the only condition for establishing the eligibility of a particular service for funding through the Mental Health Transition Fund be that it be based in the community.</p> |
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The recommended size of the Basket of Community Services is discussed in detail in Chapter 16.

5.6.3 Promoting Collaborative Care

Most people who seek professional help for a mental health problem will likely see a physician first, rather than a psychologist, social worker, or other provider. This is due primarily to the relatively larger proportion of physicians practising in the community and the manner in which the health insurance systems operate in the provinces and territories — in general, only the cost of seeing a physician is paid for by public funds, while the services of other mental health professionals, such as psychologists, often require private out-of-pocket payment.

It is important to encourage implementation of collaborative care initiatives in the development of an integrated, community-based continuum of care.

The Committee believes it important to encourage implementation of collaborative care initiatives in the development of an integrated, community-based continuum of care. Collaborative care is the most promising strategy to improve both access to, and the quality of, treatment and services at the first-line level. A recent American study of “Evidence-Based Mental Health Treatments and Services” reported on the success of collaborative care projects:

Collaborative care seeks to widen “the collaboration to include a wide variety of mental health providers, consumers and family members in the partnerships.

For example, the evaluation of one model of collaborative care using non-physician mental health specialists shows that patients with depression treated with the collaborative care model in primary care settings experienced a significantly greater reduction in symptoms over a one-year period than did patients treated with usual primary care.¹⁹⁸

The idea of collaborative care builds on “shared care” initiatives that were developed to promote greater cooperation between psychiatrists and family physicians. Collaborative care, in the sense intended by the Canadian Collaborative Mental Health Initiative (CCMHI) seeks to widen “the collaboration to include a wide variety of mental health providers, consumers and family members in the partnerships.”¹⁹⁹

Dr. Nick Kates, Chair of CCMHI, explained to the Committee that

*...there are a number of benefits to this kind of integration. The first is that it can increase access to mental health services for a large number of individuals who otherwise would not reach services. We know that 72 per cent of individuals with a mental health problem receive no mental health care over the course of a year, but 80 per cent of these individuals visit their family physicians.*²⁰⁰

Dr. Kates went on to describe the range of services that could be provided in a primary care setting, including:

¹⁹⁸ Lehman, A., Goldman, H., Dixon, L., and Churchill, R. (June 2004) Evidence-based mental health treatments and services: Examples to inform public policy. Milbank Memorial Fund, p. 14.

¹⁹⁹ Nick Kates. (17 February 2005) Testimony before the Standing Senate Committee on Social Affairs, Science and Technology, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47. The Canadian Collaborative Mental Health Initiative (CCMHI) is a consortium of 12 national organizations representing community services, consumer, family and self-help groups, dietitians, family physicians, nurses, occupational therapists, pharmacists, psychologists, psychiatrists and social workers funded by the Primary Health Care Transition Fund. The CCMHI is completing a series of 12 reports on collaborative mental health care in Canada and abroad; before its funding terminates in March 2006, CCMHI will publish toolkits designed to help patients and their families, health care professionals, and policy makers to understand the issues involved in, and work with, collaborative mental health care.

²⁰⁰ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*...early detection, health promotion and prevention, consultation, treatment, monitoring, and even some rehabilitation services, but we would stress the need to see mental health and primary care systems as complementary. One will not replace the other.*²⁰¹

Dr. Kates also told the Committee:

*We also see the benefits of pharmacists, dieticians, care navigators, peer support programs, as well as the greater involvement of consumers and family members. We believe in a model of client-centred care. We think that primary care is in a unique position to be able to do this. Our concept of client-centred care includes the development of collaborative care plans, seeing the consumer as an active partner in treatment, the development of peer support mechanisms, and involving consumers in all aspects of planning, delivering and evaluating mental health services in primary care.*²⁰²

In its published material, the CCMHI further notes that:

Providing mental health services in primary health care settings can be accomplished through various means, for example: providing direct mental health care in primary health care settings, or providing indirect mental health support to primary health care providers in primary health care settings. In the first instance, mental health care is provided by a mental health specialist; in the second, mental health care is delivered by a primary health care provider who is supported by or consults with a mental health specialist.²⁰³

It further notes that:

Collaborative mental health care takes place in a range of settings including community health centres, the offices of health care providers, an individual's home, schools, correctional facilities, or community locations such as shelters. Settings vary according to the needs and preferences of the individual, and the knowledge, training and skills of the providers. Collaboration may involve joint assessment or care delivery with several providers present with the consumer, families and caregivers, when appropriate, or it may take place through telephone or written communication. In other words,

²⁰¹ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁰² 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁰³ Gagné, M. (June 2005) What is collaborative mental health care? An introduction to the collaborative mental health care framework. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario, p. 4. www.ccmhi.ca.

effective collaboration does not require that the health care providers be situated in the same physical location.²⁰⁴

Funding for the CCMHI project expires in March 2006. The Committee believes that the work begun by the CCMHI should be pursued in two ways, and therefore recommends:

13 **That collaborative care initiatives be eligible for funding through the Mental Health Transition Fund.**

That the Knowledge Exchange Centre to be established as part of the Canadian Mental Health Commission (see Chapter 16) actively pursue the promotion of best practices in the development and implementation of collaborative care initiatives.

5.6.3.1 Human Resource Issues

In its final report on the acute care, or hospital and doctor, system,²⁰⁵ the Committee highlighted overall shortages in human resources in the health care system. Anecdotal evidence suggests that these same shortages affect the mental health sector. Throughout the health care system, an aging workforce, along with long lead times for educating and training new providers, mean that existing shortages are likely to get worse over the coming years.

It is abundantly clear that the kinds of human resource shortages that pervade the health care sector generally also affect the mental health sector.

The human resource issues raised during the Committee's hearings intersect with the need to foster collaborative care models in mental health. Although there are few hard statistics on human resources in the mental health field, it is abundantly clear that the kinds of human resource shortages that pervade the health care sector generally also affect the mental health sector. Encouraging the development of collaborative care practices that make more efficient and effective use of existing human resources in mental health is one way of addressing this shortage.

The absence of national human resource planning affects the mental health sector as much as the rest of the health care system.

Unfortunately, most recent human resource studies do not provide a detailed breakdown of the human

It is particularly important to increase the numbers of all mental health providers because so many services and supports that are critical to improving the lives of people living with mental illness are provided outside the health care system as such.

²⁰⁴ *Ibid.*, p. 3.

²⁰⁵ Standing Senate Committee on Social Affairs, Science and Technology. (October 2002) *The Health of Canadians — The federal role. Final report. Vol. 6: Recommendations for Reform.*

resource shortages in the mental health sector. A CIHI report on health care providers has noted, however, that psychologists have the highest mean age of the regulated health professions.²⁰⁶

Another example is provided by the National Symposium on Gaps in Mental Health Services for Seniors in Long-Term Care (April 2002), in which shortages of professional and non-professional participants were described as one of the most important problems in the provision of mental health services in long-term care.²⁰⁷

The absence of national human resource planning affects the mental health sector as much as the rest of the health care system. In its final report in October 2002, the Committee made several recommendations aimed at increasing the number of health care providers across the complete spectrum of health care professions and occupations. Should these recommendations be implemented, the numbers of mental health providers would increase as well.

The Committee wishes to stress that it is particularly important to increase the numbers of all mental health providers because so many services and supports that are critical to improving the lives of people living with mental illness are provided outside the health care system as such. As elsewhere in the health care system, shortages of health care providers is one of the main factors that contribute to unacceptably long wait times for access to mental health services. The Committee notes that the Canadian Psychiatric Association recently issued benchmark wait times for care for a number of psychiatric illnesses, and believes that this represents a further step towards ensuring that people have timely access to the mental health care they require.²⁰⁸

Several other human resource issues specific to the mental health field are given prominence by the need to move toward greater use of collaborative care models. The potential for widespread implementation of collaborative mental health initiatives depends to a considerable extent on the broader health care landscape – the creation of multi-disciplinary primary care teams in particular. The slow pace of primary care reform across the country is cause for particular concern.

In practical terms, the difficulties associated with reforming primary care mean that, for many years to come, many solo-practice general practitioners will continue to provide the bulk of the mental health care that their patients receive. It is well known that the fee-for-service model of physician remuneration discourages physicians from spending the extended periods of time that their patients require to help them with their mental health issues. Dr. Richard Goldbloom, Professor of Pediatrics, Dalhousie University, put it this way in his testimony to the Committee:

²⁰⁶ Canadian Institute for Health Information. (Nov. 2001) *Canada's Health Care Providers*, p. 39.

²⁰⁷ The Canadian Academy of Geriatric Psychiatry and Canadian Coalition for Seniors Mental Health. (June 2003) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 8.

²⁰⁸ Canadian Psychiatric Association. (March 2006) *Wait Time Benchmarks for Patients With Serious Psychiatric Illnesses*.

I happen to function currently as a consultant. Most of the children I see are referrals from primary care physicians.

It did not take me long to learn that the number one reason for referral is that the primary care physician realizes this will take more than 10 minutes.

Sir William Osler once said that when doctors speak of matters of principle, they invariably mean money. There is a practical problem in mental health. That is, that people are paid by the number of patients they see. As long as that is the case, you will not see much mental health care in primary care.²⁰⁹

One measure that could help family practitioners who continue to be remunerated by fee-for-service arrangements, but who wish to enhance their capacity to assist patients with mental health issues, was described to the Committee by Mr. Dermot Casey, Assistant Secretary, Health and Priorities and Suicide Prevention, for the Department of Health and Ageing, Government of Australia. Mr. Casey told the Committee that three years ago the Australian government had introduced a program designed to facilitate the delivery of care to people living with mental illness; it rewards primary care physicians financially for spending more time with people with mental health problems. He explained how this program came about and its main features:

Three years ago the Australian government had introduced a program designed to facilitate the delivery of care to people living with mental illness; it rewards primary care physicians financially for spending more time with people with mental health problems. Similar initiatives should be encouraged in Canada.

We have been told that if you are a GP and someone comes into your consulting room and you think they have a mental health problem, you keep quiet, because if you open the dialogue, you will still be there 20 or 30 minutes later, and of course, fee for service is the treatment model. We have encouraged them by saying that if it will take 20 minutes, we will pay them extra for taking the time. Currently, about 15 per cent of our GP workforce has enrolled in this program. We have about 3,500 GPs who are now enrolled in this program and recognize themselves as people who can offer slightly more and better mental health care. That is a new program.²¹⁰

The Committee believes similar initiatives should be encouraged in Canada. Provincial and territorial governments should work closely with the medical associations in their jurisdictions to adjust the fee schedules to reward primary care physicians who increase

The Committee strongly encourages provincial and territorial governments to pursue initiatives designed to remove this financial barrier and facilitate the easy flow of mental health service providers between institutional and community settings.

²⁰⁹ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²¹⁰ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 2 — Mental health, mental illness and addiction: Mental health policies and programs in selected countries, Chapter 1, p. 14. <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report2/repintnov04vol2-e.pdf>.

the time they spend with patients who have mental health problems. Some provinces have already taken measures in this direction. For example, in New Brunswick, fee-for-service physicians can bill for psychotherapy, patient counselling, and family counselling up to 4 hours per day per patient. They can also be reimbursed for time spent case conferencing with allied mental health service providers.

A study of human resource issues by the Canadian Collaborative Mental Health Initiative pointed to another issue the Committee believes must be addressed. The CCMHI report notes that “differences in compensation are especially apparent for providers who shift between institutional and community care practice environments”;²¹¹ those practising in the community setting are paid less. The Committee believes that such inequities are simply wrong and are likely to inhibit the full development of community-based services. The Committee strongly encourages provincial and territorial governments to pursue initiatives designed to remove this financial barrier and facilitate the easy flow of mental health service providers between institutional and community settings.

5.7 OTHER INITIATIVES

5.7.1 Support for Family Caregivers

Family members play an essential, at times lifesaving, role in caring for persons living with mental illness. Almost 60% of families of people living with serious mental illness are estimated to be serving in the capacity of primary caregivers, usually with little guidance, support, relief or respite.²¹² These family members often must also contend with the difficulties of navigating through a fragmented mental health system on behalf of their loved ones.

Recognizing their importance and the value of the care they provide, family caregivers were sought out and invited by the Committee to appear at public hearings in every province and territory. We have given “voice” to their concerns in Chapter 2 and have sought to respond to their input. This report addresses two key matters here: income support and respite care services.

5.7.1.1 Income Support

The Committee was told that family caregivers are being financially affected in a number of ways. For example, they often have to take time off from their jobs to care for a family member living with mental illness. In this regard, Dr. Kellie LeDrew, Clinical Director of the Newfoundland and Labrador Early Psychosis Program, noted that:

I think many times we underestimate the burdens that are placed on families. If you want to look at the cost of mental illness, oftentimes we underestimate the indirect cost of mental illness. Many of these mothers — and oftentimes it

²¹¹ Bosco, C. (September 2005) Health human resources in collaborative mental health care. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario, p. 7.

²¹² Toronto-Peel Mental Health Implementation Task Force. (December, 2002) *The Time Has Come: Make It Happen*. A mental health action plan for Toronto and Peel, p. xv.

*is the mother — have had to take time off work. I have had to give numerous notes for mothers who had to take time off work to stay home so that the son does not have to go into the hospital. They do not want to leave him because they are afraid something will happen.*²¹³

The Committee believes that caregivers should receive some form of financial assistance from government when they have to leave work temporarily to care for a family member who is mentally ill. A number of compelling reasons lead us to this belief:

- *Persons living with mental illness* benefit by receiving long-term help from a familiar source, outside an institutional setting. With this help they may also be spared contact with the criminal justice system or homelessness.
- *Caregivers* benefit by maintaining stable employment over time. They are also better able to maintain a supportive relationship with the affected family member.
- *Employers* benefit from being able to retain valued staff and avoid costs associated with other forms of leave (e.g., sick leave) that may be relied on when leave to care for a family member is unavailable or available only for brief periods of time.
- *Governments* benefit by keeping caregivers in the workforce and persons living with mental illness out of hospitals, long-term care facilities, prisons, and off the streets, all of which will result in cost savings to the public purse.

Caregivers should receive some form of financial assistance from government when they have to leave work temporarily to care for a family member who is mentally ill.

The Committee is aware that Compassionate Care Benefits are currently available to eligible Canadians through Employment Insurance (EI). However, these benefits are restricted to persons who have to be absent from work to provide care or support to a gravely ill family member at risk of dying within six months.²¹⁴ Recent reports suggest that this program has been seriously under-utilized by its target constituency, in part at least because of the restrictive eligibility criteria that are currently in place.

Given the enormous surplus in the EI account²¹⁵ and the recent decision of the Supreme Court of Canada²¹⁶ affirming Parliament's constitutional authority to adapt the EI plan to the

²¹³ 15 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²¹⁴ For a more detailed explanation, see Employment Insurance (EI) Compassionate Care Benefits, http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/ei/types/compassionate_care.shtml&hs=tyt#Who.

²¹⁵ In her November 2004 Report, the Auditor General indicated that the accumulated surplus in the EI account had risen to \$46 billion. See: Office of the Auditor General of Canada. (November 2004) Report, Chapter 8. <http://www.oag-bvg.gc.ca/domino/reports.nsf/html/20041108ce.html#ch8hd3b>.

²¹⁶ Reference re *Employment Insurance Act* (Can.), ss. 22 and 23, 2005 SCC 56. <http://www.lexum.umontreal.ca/csc-scc/en/rec/html/2005scc056.wpd.html>.

new realities of the workplace, the Committee believes that it is appropriate to make Compassionate Care Benefits more widely available. Therefore, the Committee recommends:

14 **That compassionate care benefits be payable up to a maximum of 6 weeks within a two-year period to a person who has to be absent from work to provide care or support to a family member living with mental illness who is considered to be at risk of hospitalization, placement in a long-term care facility, imprisonment, or homelessness, within 6 months.**

That eligibility for compassionate care benefits be determined on the advice of mental health professionals and that recipients of compassionate care benefits be exempt from the two-week waiting period before EI benefits begin.

5.7.1.2 *Respite Care Services*

The responsibility of providing care and support to a family member living with mental illness can place caregivers at risk of burnout. Brenda McPherson, Provincial Coordinator of Psychiatric Patient Advocate Services for New Brunswick, testified that:

To avoid caregiver burnout, the Committee believes that respite care services available to families must be significantly improved.

...many of our caregivers or parents of these [psychiatric] patients are literally burnt[out]. They have been caring for these individuals since the age of 12, 13 or 14. The caregivers have gone through the justice system, they have gone through foster home systems, and so on. By the time their children are 25 and 30...the caregivers are ... burnt[out], and they have access to little or no resources. That is why I think it is important that the federal government play a role, and partner with the provincial government to enhance the services and the resources that the province has.²¹⁷

To avoid caregiver burnout, the Committee believes that respite care services available to families must be significantly improved. A variety of models were suggested, including:

- having a public health nurse make home visits to the families of persons recently diagnosed with mental illness to offer information and support;²¹⁸
- providing in-home respite care that frees caregivers to go to their own medical or other appointments, attend support groups, or shop for groceries;²¹⁹

²¹⁷ 11 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²¹⁸ Doris Ray, 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

- establishing adult daycare services;²²⁰
- improving institutional respite care by making it available more often and for longer periods.²²¹

Given the diverse needs of family caregivers, and recognizing that these needs may shift over time, it seems logical to make a variety of respite care services available. Therefore, the Committee recommends:

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| 15 | That initiatives designed to make respite care services more widely available to family caregivers, and better adapted to the needs of individual clients as they change over time, be eligible for funding through the Mental Health Transition Fund. |
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²¹⁹ Menna MacIssac, 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²²⁰ Christine Davis, 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²²¹ Penny MacCourt, 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

6.1 INTRODUCTION

The greatest omission in the work that I see is that it fails to stress the reality that most of the mental health disorders affecting Canadians today begin in childhood and adolescence. Failure to recognize this fact leads us to dealing with a stage-four cancer, often with major secondary effects, instead of a stage-one or stage-two disease. Like obesity, mental health issues, if not addressed early in life, threaten to bankrupt our health care system. —Diane Sacks²²²

There are a great many children and youth who are living with mental illness. It is conservatively estimated that as many as 15%²²³ are affected at any given time, a total of some 1.2 million young Canadians who live with anxiety, attention deficit, depression, addiction, and other disorders.²²⁴ Further, given that families are usually directly involved in the care and support of their younger members, the impact of these high rates of illness is compounded. When a child or young person lives with mental illness or addiction, so too do his or her family caregivers.

...a total of some 1.2 million young Canadians live with anxiety, attention deficit, depression, addiction, and other disorders.

Although one might expect that these high rates of prevalence, coupled with the ready supply of advocates (i.e., parents), would have resulted in a well organized, appropriately funded mental health system capable of attending to the needs of children and youth, this is not the case. The Committee learned from those who appeared before it that the system is fragmented and under-funded, that intervention occurs far later than is necessary, that there is a critical shortage of mental health professionals, and that young people and their families are not being involved in workable, long-term solutions to their serious mental health problems.

Children and youth are at a significant disadvantage when compared to other demographic groups affected by mental illness, in that the failings of the mental health system affect them more acutely and severely. The Committee believes it is imperative to move aggressively to tackle key problems now — with other changes to follow.

²²² 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²²³ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 5, Section 5.1.2, p. 86.

²²⁴ *Ibid.*, pp. 86-87.

6.2 EARLY INTERVENTION

The importance of early intervention cannot be overstated. When symptoms of distress or illness first appear in a child or young person, regardless of age, family caregivers, health professionals and educators should intervene immediately.

The importance of early intervention cannot be overstated.

Also, these interventions must be sustained, where necessary, through the transition into school, and thereafter into adulthood. The Committee shares the view of Dr. Ian Manion, a psychologist, who emphasized the importance of reaching children and youth in all stages of their development:

If you focus solely on one area you create another garrison. You are saying that that is where the funds should be directed, and that means that a generation of middle-year children and youth lose out, or a generation of adolescents loses out. Of course, if you lose a generation of adolescents you are actually losing the next generation of parents, who will parent those zero-to-three-year-old children down the road. Therefore, you need to have a full appreciation of the continuum of care along a developmental continuum.²²⁵

Mental illness and addiction do not respect arbitrary cut-off ages. For this reason, the Committee does not support targeting mental health funds for children and youth in a narrow age range. Instead, our focus will be on the establishment of a fully integrated and seamless continuum of services through to and including adulthood.

...we advocate an end to the practice of terminating mental health or social services when the client has reached a predetermined age (e.g., 16 or 18 years), after which he or she is expected to seek help through the adult system(s).

Further, we will advocate an end to the practice of terminating mental health or social services — *both* of which are important to good mental health — when the client has reached a predetermined age (e.g., 16 or 18 years), after which he or she is expected to seek help through the adult system(s).

6.2.1 The Pre-School Years

While much of the testimony heard by the Committee emphasized the importance of early intervention, most often it was discussed as applicable to school-age children. The logic and convenience of locating mental health interventions within the education system must not blind us, however, to the reality that problems can and do arise prior to enrolment in school. As Sharon Steinhauer, a member of the Alberta Mental Health Board, explained:

We know that the risk factors come out of the kinds of family and community environments that kids live in.... The question is: Do we have ways of identifying children who are at risk, and do we have ways of capturing them

²²⁵ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

into support networks so that, in fact, we are mitigating some of the risks that may make their family vulnerable?

The first place is where kids are raised, of course, and that is families; secondly, is in school. Thus those early years, which the ECD [Early Childhood Development] strategy is trying to address, is the preschool piece. We are trying Head Start programs and a number of other avenues to try to identify those kids who may need more support than is naturally available to them.²²⁶

As children mature, they will bring their emerging mental health problems with them into the school environment. Michelle Forge, Superintendent of Student Services at the Bluewater District School Board, noted that:

When they do, they will be better for having had a teacher who has been able to help them understand what school looks like and how to make those transitions. It also helps the preschool team to navigate the system. We are a system, and we are very different from anybody else. We know it, and we need to provide the navigation tools and people to do that.²²⁷

The pre-school years present two challenges. The first is to identify and provide services to those children who are living with, or who are at risk of developing, mental illness. The second is to manage effectively the transition from early childhood (0-5 years) into the school system. The Committee recommends:

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| 16 | That school boards mandate the establishment of school-based teams made up of social workers, child/youth workers and teachers to help family caregivers navigate and access the mental health services their children and youth require, and that these teams make use of a variety of treatment techniques and work across disciplines. |
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6.2.2 The School-Age Years

Many of the Committee's witnesses spoke of the need to ensure that schools are better equipped to handle children's mental health issues than they are now. Dr. Richard Goldbloom, Professor of Pediatrics, went so far as to remark that, "I see the school as the most

Many of the Committee's witnesses spoke of the need to ensure that schools are better equipped to handle children's mental health issues than they are now.

²²⁶ 9 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/21eva-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²²⁷ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

underdeveloped site for effective health care of any in the country.”²²⁸ He went on to suggest that:

*...we need a major move of mental health services from their present locations in most communities into the schools. The school is children's natural habitat. For six or eight hours a day, it is where they are, it is where their parents often come and it is where you can deal with the problems in collaboration with the teachers.*²²⁹

Dr. John Service, Chair of the Canadian Alliance on Mental Illness and Mental Health, echoed these comments:

If we look at just one group, that is young adults, and we ask young adults why they do not access mental health services, they will often tell us it is because they are in large hospitals, because they are in settings that they feel very uncomfortable going to. ... The way we position our services often dictates that they will not use them very effectively. That is a serious issue. ...

*Another example that I could use from my own experience as a psychologist for 15 years with children, adolescents and families in Nova Scotia, is that we had difficulty getting children and their families to feel comfortable coming to the hospital. We negotiated with the county school board an agreement where we would offer our mental health services in the schools. That was much more effective. People felt much more comfortable coming and we had access to the teachers.*²³⁰

There was agreement also regarding the importance of teachers having the training necessary to recognize better mental health issues in their students and to help them find effective treatment, rather than, as now, referring students to already overburdened emergency rooms or relegating them to long waiting lists.

The Committee stresses the importance of teachers having the training necessary to recognize better mental health issues in their students and to help them find effective treatment.

Dr. Mimi Israël, Psychiatrist-in-Chief at the Douglas Hospital (Montreal), called for investment

Development of the school as a site for the effective delivery of mental health services is essential.

²²⁸ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²²⁹ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²³⁰ 21 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

in the training of non-mental health professionals, including teachers. Specifically, she stated that “we should produce a mental health curriculum that would be integrated into the educational programs of teachers, daycare workers and other health professionals.”²³¹

Judy Hills, Executive Director of the Canadian Psychiatric Research Foundation, described one such initiative undertaken by her organization in recognition of the fact that “...research shows that the first person youth go to for help is the teacher.”²³² She commented that:

...teachers were having problems coping with things changing [in the school system] so quickly. They asked if we would put together a guide to help them until they could get help for the children they were working with. They were facing waiting lists for referrals of up to a year and a half for children in their classrooms.

The foundation gathered together a group of experts in the field of education. We had principals, teachers, special education people and youth themselves involved in putting together a handbook entitled “When Something's Wrong.”²³³

Ms. Hills went on to clarify that:

We know that teachers cannot be diagnosticians, and we do not want them to be that, but we do want them to have some skills in early identification and to understand some of the mood and behaviour disorders that might be caused by mental disorders. With that, they have a basis on which to go forward.²³⁴

Development of the school as a site for the effective delivery of mental health services involves several key steps. First, its potential must be recognized. Second, those services must be relocated from other hospital or community-based sites, or established as new services. Third, teachers must be provided with the time and resources to take on this new, more involved role. Therefore, the Committee recommends:

²³¹ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²³² 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²³³ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²³⁴ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

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| 17 | <p>That mental health services for children and youth be provided in the school setting by the school-based mental health teams recommended in previous section 6.2.1.</p> <p>That teachers be trained so that they can be involved in the early identification of mental illness.</p> <p>That teachers be given the time and the practical resources and supports necessary to take on this new role.</p> |
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6.2.2.1 Mental Health Screenings

It was suggested to the Committee that another way of involving schools could be through their administration of screening tools for mental illness. This is a matter of some debate. For example, in her testimony to the Committee, Carolyn Mayeur, recounting her daughter's experience, argued in favour of general screening programs:

I believe there should be regular screening for mental health through all the grades. Danielle had a chemical imbalance that started when she was very young, but there was no screening mechanism. We could have maybe prevented a lot of what happened if we had caught it early.²³⁵

Others, including Dr. Diane Sacks, Past President of the Canadian Paediatric Society, favour a more targeted approach:

It is positive to recognize that services need to be involved in the school system. The next step is to recognize that we are now able to offer available, inexpensive, easy-to-apply and validated tools for identifying many of these disorders in children. These tools need to be utilized [with] a high risk, definable population identified within the school system.

What is this population? These are the children who are frequently absent, failing or dropping out. They need to be tagged and automatically screened for mental health disorders. We do not need to wait until they are in prisons to test them and find out, as they did in the U.S., that up to 80 per cent of prison residents have diagnosable conditions.²³⁶

²³⁵ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²³⁶ 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Dr. Norman Hoffman, Director of the Student Mental Health Service at McGill University, was more cautious. He stated that:

We see a trend towards wanting to make these fast diagnoses. Screening programs such as depression screening may increase awareness of the problem of depression, but often all it does is support the idea that depression is a singular biological entity. This idea is highly promoted by the pharmaceutical industry, but has no support in the literature.

Depressed moods are a complex problem. Twenty years ago, students would come to see us and they would say, "I feel depressed, I feel down." Now they come in and say, "I think I have depression." We say, "What do you mean? How are you feeling? What is going on in your life?" They answer, "No, I have depression." People want fast answers and fast solutions, but they do not work.²³⁷

Later, he continued by offering an alternative to general screening programs:

We need to have school systems where the teacher-to-student ratio is small enough that teachers know their kids. We do not need to do a depression screening in a school if a teacher knows their kids. They will know which kids are troubled.²³⁸

The Committee acknowledges the support shown for a variety of approaches to screening programs. While we are very strongly in favour of early diagnosis, we are mindful not only of the criticisms, but also of the roadblocks to implementing screening programs in schools. These fall into two general categories.

While we are very strongly in favour of early diagnosis, we are mindful of the roadblocks to implementing screening programs in schools.

6.2.2.1.1 Legal Roadblocks

As discussed in Chapter 4, Section 4, mental health services are primarily a responsibility of the provinces and territories, whose collaboration would therefore be essential to the implementation of any national strategy of mental health screening. In addition, each jurisdiction's laws regarding the provision of health services in a school setting, consent to medical care, privacy of personal information, and admitting a student for treatment for a specific illness would also have to be followed.

The Committee believes that, to screen students for possible mental health concerns, informed consent is necessary, even though, depending on applicable provincial and territorial legislation, a mental health screening may or may not be among the medical services that require consent. Consent should be obtained from the appropriate person, the student in some cases and his or her family caregiver in others.

²³⁷ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²³⁸ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Provincial and territorial legislation varies with respect to the age at which a person is considered capable of consenting to, or refusing, treatment. Legislation notwithstanding, age is not determinative; a minor or person below a statutory age may well be capable of consenting to medical treatment if he or she understands its nature and consequences.

The Committee believes that, to screen students for possible mental health concerns, informed consent is necessary.

For consent to be valid it must be both free and fully informed, the latter meaning that the nature, gravity and any risks of the mental health screening must be conveyed to the person to be screened. Understandable answers must also be given to specific questions asked by the person concerned about the procedure or process. A requirement that consent be given without undue influence or coercion may be particularly important when a student who has not yet reached the age of consent is asked to agree to a mental health screening in the presence of school authorities, health professionals and peers.

Mental health screenings in schools would require appropriate measures to be taken to protect the confidentiality of each student's personal information. If a student is competent and capable of providing his or her own consent, it becomes a legal question whether the mental health screening and its results may be disclosed to the student's family caregiver. The law is not consistent across Canada. In any given situation a family caregiver may be precluded from receiving, being entitled to receive, or being required to receive information about the student's health status and care.

Treatment that might follow a mental health screening would also be subject to significant legal implications. The law relating to consent and confidentiality of information would remain applicable, but the legal requirements with respect to treatment would not necessarily be the same as for the initial mental health screening. Because the nature and consequences of mental health treatment are usually more serious than assessment itself, it is possible that a person who is capable of consenting to a screening, and to controlling the disclosure of its results, would not be capable of consenting to follow-up treatment, or of preventing others (his or her family caregiver, for example) from being advised of the treatment options available.

6.2.2.1.2 Practical Roadblocks

In addition to the inconsistency of the law pertaining to mental health screenings, there is also the question of what school authorities or family caregivers would do with the information the screening might reveal. At present, only a small percentage of people with mental illness or addiction, including children, actually seek help from health professionals.²³⁹ Yet the existing system is already overburdened.

It seems unlikely that there would be a sufficient number of mental health professionals available in the near term to assist these children and youth. Given this situation, nothing would be accomplished by the screening; indeed, more harm could be done.

²³⁹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 8, Section 8.2.6, p. 163.

If mental health screenings were widely administered in schools, one could reasonably expect that significantly more children and youth would be diagnosed as living with mental illness. Carole Tooton, Executive Director of the Nova Scotia Division of the Canadian Mental Health Association, cautioned the Committee that:

We are somewhat hesitant now to do presentations in the schools. We get many calls especially for grade 11 classes, where part of the curriculum deals with psychology. We worry that after our presentation that the school does not have a system in place to deal with any problems that arise out of the presentation. We need to know that the teachers and guidance councillors have the proper strategy to deal with a student who realizes he or she might have a problem with depression or thoughts of suicide.

We are hesitant because we know that a proper follow-up strategy is essential to the success of our program. If the school does not have a strategy, it struggles to find the proper professionals in the system.²⁴⁰

Indeed, even if the suggested strategy is in place, for reasons discussed in Section 6.3 of this chapter it seems unlikely that there would be a sufficient number of mental health professionals available in the near term to assist these children and youth. Given this situation, nothing would be accomplished by the screening; indeed, more harm could be done.

In summary, while the Committee believes that mental health screenings in schools may offer benefits, there are two reasons why a large-scale screening program should not be started at this time. First, existing inconsistencies among provincial and territorial laws render a national initiative unworkable; unfortunately, there appears to be no current appetite for the extensive law reform needed to resolve these inconsistencies on a Canada-wide basis.

Second, while approaches targeted at specific groups of the student population offer somewhat more promise, the existing shortage of health professionals remains a significant impediment.

Perhaps once the mental health system has been reformed, and either its capacity or efficiency or both have been increased, some limited screening programs — carried out within individual jurisdictions — could be considered.

6.2.2.2 Stigma and Discrimination

The issue of stigma and discrimination arises throughout this report and is examined in greater detail in Chapter 16.²⁴¹ Nonetheless, the Committee feels it is necessary to emphasize

²⁴⁰ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁴¹ For a full discussion of stigma and discrimination see also Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 3.

here the importance of implementing early education and awareness about mental illness in schools.

Often, stigma comes from a lack of knowledge. This ignorance is pervasive among all Canadians. The rationale for targeting educational programs at younger people is simple. As Dr. Simon Davidson, Chief of Psychiatry at the Children’s Hospital of Eastern Ontario, pointed out, “we have learned that it is relatively simple to destigmatize mental health with youth. I do not think the same is true of adults.”²⁴²

“We have learned that it is relatively simple to destigmatize mental health with youth. I do not think the same is true of adults.” - Dr. Simon Davidson

When resources are scarce, it is best to target information at those who are most receptive to it.

In short, when resources are scarce, it is best to target information at those who are most receptive to it. Therefore, the Committee recommends:

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| 18 | That students be educated in school about mental illness and its prevention, and that the Canadian Mental Health Commission (see Chapter 16) work closely with educators to develop appropriate promotion campaigns in order to reduce stigma and discrimination. |
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6.2.3 Post-School — Making the Transition to the Adult System

As stated earlier in this chapter, there is no end date for mental illness. The same cannot be said for the mental health and social services available to children and youth. This common problem is one which the Committee believes *must not* be allowed to continue.

6.2.3.1 Mental Health Services

Abrupt termination of essential services has been rightly characterized as akin to falling off a cliff. Yet this is what happens all too often when young people reach a predetermined age, set out in law or policy, at which they become ineligible for “children’s” mental health services. One day they are eligible, the next day — their birthday — they are not. As Dr. Ashok Malla, Head of Research at the Douglas Hospital, noted:

When young people reach a predetermined age, set out in law or policy, at which they become ineligible for “children’s” mental health services. One day they are eligible, the next day — their birthday — they are not.

...separation of child/adolescent from adult services I think is artificial and it is counterproductive. While resources for this age group [should] be protected at all costs, disorders with onset during adolescence must be treated within a system that is continuous, so that the expertise is available where the person needs care, as opposed to the person going for...X-number of years to this unit

²⁴² 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*and then being transferred when they turn that magical age of 18 to another set of programs.*²⁴³

Some of the situations described to the Committee were quite nonsensical. For example, Dr. Linda Bayers, Executive Director of the Self Help Connection, told us that:

*As for this business of 17 and 18, one time they opened up a mental health clinic next to a high school, which was a hop, skip and a jump away but the kids could not access it unless they were 19 years old. What is wrong with this picture? We have to get a lot smarter about helping people in that age group.*²⁴⁴

While one might be tempted to just shake one's head at whatever rationale might underlie decisions of this type, the consequences are very real. Phyllis Grant-Parker described her son's experience this way:

*When you are young and you have mental illness, it is like the system expects you to immediately be an independent adult. In Ottawa, where we live, we could not find him the necessary age-appropriate treatment. The Children's Hospital of Eastern Ontario — CHEO — had no program. The Ottawa First Episode Psychosis Clinic at the Ottawa Hospital had a six-month wait. As a result, my son was hospitalized in a tertiary care hospital housed with chronically ill adults and no rehabilitation program. It is a pretty bleak forecast for a teenager and for his family.*²⁴⁵

Children and youth require specialized mental health services. But there is no good reason why such services should exist in isolation from the larger mental health system. The current practice of “guarding one's own turf,” a habit that has resulted in individuals and organizations operating alone, in silos, must cease.

The current practice of “guarding one's own turf,” a habit that has resulted in individuals and organizations operating alone, in silos, must cease.

It is the responsibility of mental health professionals to work in concert to tear down barriers within and between the adult and children's systems. All treatment services, be they community-, school- or hospital-based, should be fully integrated to ensure children and youth receive age appropriate interventions for as long as they are needed.

Therefore, the Committee recommends:

²⁴³ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁴⁴ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁴⁵ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

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- 19 That provincial and territorial governments work to eliminate any legislative, regulatory or program “silos” that inhibit their ability to deal in an appropriate fashion with the transition from adolescence to adulthood, and that they adopt the following measures:
- Determine age cut-offs for mental health services for children and youth by clinical, rather than budgetary or other bureaucratic, considerations.
 - Where age cut-offs are employed, link services for children and youth to adult services to ensure a seamless transition.
 - Where age cut-offs are employed, avoid any “gaps” of time where individuals are ineligible for treatment under both the children and youth and the adult systems

6.2.3.2 Social Services

While age cut-offs have resulted in certain nonsensical outcomes in the context of mental health services, those in the arena of social services at times defy belief. Reproduced below, in full, is an exchange between Andy Cox, Mental Health Advocate at the IWK Children’s Hospital in Halifax, and the Committee’s Chair. This discussion occurred at the Committee’s public hearings in Halifax. While not involving a person living with a mental illness, it is illustrative of the gaps in services such people face on an ongoing basis:

Mr. Cox: *For the first part, I will explain by giving an example. We have a young fellow who is 18 on our inpatient unit. He has been there since October [seven months]. He does not have a mental illness, or any mental health issues. Community services would not house this young man. He came to the ER at the IWK, was admitted, and we have been fighting to find him a place to live. We have three or four cases like that on our inpatient list.*

The Chairman: *Why was he admitted if he did not have a problem?*

Mr. Cox: *Community Services gave up on him. He is blind.*

The Chairman: *You gave him a bed in a hospital because the Department of Community Services, to use your words, gave up on him?*

Mr. Cox: *Yes, and we have been fighting it, appealing it.*

The Chairman: *He is occupying a hospital bed because there is nowhere else to go and yet he is not sick?*

Mr. Cox: *No, he is not.*

The Chairman: He has not committed a crime?

Mr. Cox: No, he has not.

The Chairman: You understand how, to ordinary people, this sounds absolutely ridiculous, as well as extremely expensive.

Mr. Cox: That is not rare.

The Chairman: This is not totally unique?

Mr. Cox: No, it is not.²⁴⁶

The problem appears to originate in the wording of certain provincial statutes. As Christine Brennan, Supervisor of Youth and Senior Services at the Office of the Ombudsman for Nova Scotia, explained:

No person living with a mental illness should be left to languish in a legislative void between the children and youth and the adult systems.

...you have to understand that under the Children and Family Services Act in our province [Nova Scotia], it says the minister, until the age of 15, shall provide services, and between 16 and 18 the minister may provide services. "Shall" has been legislatively interpreted to be "you have to." We have noticed a service gap for those youth aged 16 to 17 because the act says the minister "may."

Generally, a lot of the youth that need those types of services do not follow case plans that are set for them so they are problem youth. It is easier to terminate a care agreement or not provide those services, which is problematic because the youth that need the services are not getting them because of their problem behaviour.²⁴⁷

The Committee is of the view that *both* mental health *and* social services are critical to staying well. While a seamless continuum of either type of service is beneficial to children and youth, tying the two systems together augments their positive effects.

No person living with a mental illness should be left to languish in a legislative void between the children and youth and the adult systems.

Therefore, the Committee recommends:

²⁴⁶ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁴⁷ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

20 That provincial and territorial governments coordinate mental health and social services, and pay particular attention in this regard to ensuring that age cut-offs for social services for children and youth be synchronized with those established for mental health services.

6.3 SHORTAGE OF CHILD AND ADOLESCENT MENTAL HEALTH PROFESSIONALS

Canadians have grown accustomed to hearing about a shortage of health professionals in this country. Neither the mental health system, nor the sub-system serving children and youth, has escaped these shortfalls.

The Committee was told repeatedly that there is a need for a much greater number of mental health professionals across Canada, particularly those who specialize in treating young people. Dr. Nasreen Roberts, Director of the Adolescent Urgent Consultation and Inpatient Service at Hotel Dieu Hospital in Kingston, provided one example of this in her testimony:

Providing very quick care, providing an urgent consult service, is important. I have just done a waiting list from across the country for all the 16 medical schools. The waiting list for triage is two weeks to four weeks. The waiting list to see somebody varies between eight weeks to 18 months.

There are less than 500 child and adolescent psychiatrists in the country. If you look at only 14 percent of the severely disordered kids in the general population, that translates to 800,000 kids across Canada. That is taking just the severe disorders; I am not including the 22 percent that I [think] should be [treated]. Those are very important numbers.²⁴⁸

Given that only ten fully trained child psychiatrists graduate from medical school each year,²⁴⁹ the problem Dr. Roberts refers to will likely be with us for some time.

It is not just a question of increasing the number of psychiatric specialists, however. Shortages of other mental health professionals who specialize in treating children and youth, including psychologists, nurses and social workers, must also be addressed. Therefore, the Committee recommends:

²⁴⁸ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁴⁹ Global Business Roundtable on Addiction and Mental Health. (September 2005) Special Report to the Premiers of Canada: Guidelines for Working Parents to Promote and Protect the Mental Health of Their Children, p. 2. Available at: www.mentalhealthroundtable.ca.

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- 21 That governments take immediate steps to address the shortage of mental health professionals who specialize in treating children and youth.

6.3.1 Transitional Measures

While the Committee agrees that waiting times must be reduced, we realize that increasing capacity within the system, particularly the training capacity for those mental health professionals who specialize in treating young people, will be a very lengthy process.

It is not just a question of increasing the number of psychiatric specialists, however. Shortages of other mental health professionals who specialize in treating children and youth, including psychologists, nurses and social workers, must also be addressed.

The Committee believes it important, therefore, to explore remedies that will bring some relief in the near term. We believe that tele-psychiatry, the use of alternative treatment models, and case conferencing, have that potential. These transitional measures will help to bridge the gap during a period of restructuring designed to enhance the ability of the mental health system to assist children and youth.

6.3.1.1 Sharing Existing Resources — Tele-Psychiatry

The Committee has heard testimony regarding the benefits offered by new technologies. One of these — tele-psychiatry — will be examined in detail in Chapter 12. However, the Committee raises the matter here as it has particular application to mental health services for children and youth.

Tele-psychiatry will permit the sharing of existing resources with under-served regions only if a basic level of mental health service is already available in those communities.

Shortages of mental health professionals are usually experienced most acutely in rural and remote areas. Those living in communities with limited or no access to mental health services may be forced to travel great distances for treatment. One of the suggestions put to the Committee to deal with the situation in such communities was increased use of tele-psychiatry. Michelle Forge explained that:

We do not have a children's psychiatrist in our jurisdiction. Quite frankly, the wonderful access that we have had through tele-psychiatry...I believe it is over 200 psychiatric consultations, has allowed us to do things at the community level that we would not have been able to do otherwise. We need that access. We do not necessarily need it all the time, but we need the access and we need a pediatric community that is willing to support it.²⁵⁰

²⁵⁰ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The key here is access to external expertise by *local* health professionals, be they psychologists, nurses, social workers or primary care physicians. Tele-psychiatry will permit the sharing of existing resources with under-serviced regions only if a basic level of mental health service is already available in those communities. Also, local health professionals and their clients must be willing and able to make use of the technology and the advice provided by consultants at a distance.

Therefore, the Committee recommends:

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| 22 | <p>That the use of tele-psychiatry be increased in rural and remote areas, to facilitate the sharing of mental health personnel who specialize in treating children and youth with these communities.</p> <p>That tele-psychiatry be employed both for consultations and for the purposes of education and training of health professionals who work in rural and remote areas.</p> |
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6.3.1.2 Emphasizing Alternative Treatment Models — Group Therapy

A number of experts proposed the use of alternative treatment models, particularly group therapy, as a way to reduce waiting lists. Andy Cox stated that:

*...my top solution is more groups have to be organized. We have youth sitting on a wait list when we can bring them together and start talking earlier about mental illness and, therefore, we will know in what direction to refer these youth.*²⁵¹

His view was echoed by Dr. Richard Goldbloom, who presented a case described by the British Paediatric Association in which group therapy was used with children living with Attention Deficit and Hyperactivity Disorder. According to Dr. Goldbloom:

The shortage of mental health professionals who specialize in treating children and youth is clearly critical.

The waiting list of children referred for assessment of possible attention deficit disorder had tripled over a one-year period. To deal with this, they held patient information sessions targeted at parents who had been on the clinic wait list for nine months or more.

*They reduced the wait list. Many of these children were put in treatment through group sessions. They reduced the wait list from 20 months to zero over a period of only seven months. It can be done.*²⁵²

²⁵¹ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁵² 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The shortage of mental health professionals who specialize in treating children and youth is clearly critical. However, by educating practitioners in how best to manage waiting lists, particularly through the use of alternative therapies, it may be possible to lessen the impact of the shortage. Therefore, the Committee recommends:

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| 23 | That standardized, evidence-based group therapies be used, where clinically appropriate, to reduce wait times for children and youth who need access to mental health services. |
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6.3.1.3 Working Cooperatively — Case Conferencing

As the information in this chapter clearly shows, children and youth are not well served by the mental health system. Hence, all options for improving service levels must be explored, including case conferencing.

Barbara Whitenect, then Acting Director of Child and Youth Services for the New Brunswick Department of Health and Wellness, put it this way:

One approach we have used in New Brunswick is comprehensive case conferencing. We talk about case conferencing a lot. ... Often, because of demands for service, wait lists or mandates, people do not make the time.

We have to look at mandating that and linking it to funding. People have to come together and bring their resources for children, their issues, to the table. ... It is important that we know and understand the dynamics. We will if we are sitting at the same table.²⁵³

Ms. Whitenect went on to describe the positive impact flowing from the implementation of the *Youth Criminal Justice Act*:

When a young person commits an offence, the judge orders the community partners to have a case conference before sentencing. It is too bad that the young person has to commit an offence before we can legislate case conferencing. ...

People say, "I have waiting lists," and this and that. If a judge says "You will do it," you do it. We have seen some positive results. It has not overtaxed our people because it is only in those very difficult cases, those high-need situations that we all encounter that we throw our resources onto the table.

²⁵³ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*I will not overemphasize that, but if we start acting strategically and say our funding dollars are linked to doing these case conferences, thus reshaping the way people do their work, then we can achieve that.*²⁵⁴

The Committee believes that case conferencing has the potential to increase the efficiency of the mental health system, while also reducing costs. It is a further example of a transitional measure that may be of some assistance in compensating for the existing shortage of mental health professionals who specialize in treating children and youth. Therefore, we recommend:

The Committee believes that case conferencing has the potential to increase the efficiency of the mental health system, while also reducing costs.

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- 24 **That provincial and territorial governments encourage their health, education and justice institutions to work closely together in order to provide seamless access to mental health services for children and youth.**
- That greater use be made of case conferencing so as to coordinate and prioritize mental health service delivery to children and youth.**

6.4 INCLUSION OF YOUTH AND FAMILY CAREGIVERS IN TREATMENT

Children and youth pose a particular challenge to mental health professionals. Their bodies and minds are continually growing and changing. Adapting treatment interventions to this reality is a delicate process, one that must be approached with a healthy respect for the client and his/her family caregivers.

The Committee believes that it is important to include children and youth and their family caregivers at every stage of the process.

Where the family unit is dysfunctional it should be treated as a whole, with all family members provided the assistance they need.

The Committee believes that it is important to include children and youth and their family caregivers at every stage of the process. Judy Finlay, Chief Advocate for the Ontario Office of Child & Family Services Advocacy, provided the following rationale:

If we begin to view parents and children as collaborators in assessment, planning, delivery and evaluation of mental health services, it will force a family-based intervention, with the child and the family at the centre. As long as we have a provider-driven system, we will always have the families on the

²⁵⁴ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*periphery. We need to move to a family-driven model that enables the child and the family to do well in their community.*²⁵⁵

Shifting to this model of service delivery will not be easy. It will require a change in mindset that, to date, has resulted in the mental health system being structured to suit the needs of institutions and providers, not clients. As a first step, it must be recognized that children and youth, and their family caregivers, are full and equal partners — capable of defining the solutions that best meet their own needs. The Committee strongly supports this approach and therefore recommends:

Shifting to this model of service delivery will not be easy. It will require a change in mindset that, to date, has resulted in the mental health system being structured to suit the needs of institutions and providers, not clients.

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- 25 **That evidence-based family therapies be employed so that all family members are provided the assistance they need.**
- That professionals interacting with children and youth with mental illness be offered training opportunities to ensure that they can properly address the mental health needs of their younger clients.**
- That family-based treatment of mental illness be integrated into the curriculum of mental health professionals and primary care physicians.**
- That professionals interacting with family caregivers be compensated for this time, in addition to the time spent with the young person living with mental illness.**
- That all practitioners working with children and youth be trained in children’s rights.**

6.5 AUTISM

In its first report, the Committee described hearing from mental health professionals who outlined barriers to service delivery, and from family caregivers who spoke of the emotional and financial toll associated with caring for those living with autism. Their statements, in conjunction with a review of the literature, led us then to characterize autism as a “mental disorder.” In retrospect, we should have consulted with persons living with autism before taking this position.

During the public hearings that followed the release of our interim reports on mental health, mental illness and addiction, the Committee again heard testimony on this issue. This time, however, we heard sharply divergent views on what autism is and how the mental health system should respond to it.

²⁵⁵ 6 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Norah Whitney, whose child is living with autism, stated that:

*Without effective treatment, autism is a lifelong disorder that results in the placing of over 90 per cent of untreated children in group homes and residential facilities. Only 1 in 64 children will improve without treatment.*²⁵⁶

Later she noted that:

*...almost 50 per cent of children with autism who receive treatment before they enter school, ideally at age 2, will go on to become completely indistinguishable from their peers. In other words, with this treatment, there is a 47 per cent recovery rate. Now, I know many people do not believe in recovery when it comes to autism, but I have seen these children with my own eyes, and if I did not know better, I would never be able to detect one trace of autism in their little bodies.*²⁵⁷

Ms. Whitney is of the view that autism is an illness²⁵⁸ that if left untreated will have serious consequences for affected individuals, and their family caregivers. She advocates the early use of Intensive Behavioral Intervention (IBI), describing it as “the only effective treatment that we have for autism.”²⁵⁹ Also, she points out that family caregivers are experiencing financial hardships associated with the high cost of IBI and the fact that often only limited assistance is available under provincial health plans.

Persons living with autism, such as Michelle Dawson, took strong exception to these arguments. She countered that:

Autistics have been portrayed by autism advocates in the most dire and horrific terms. We destroy ourselves, our families, and the economy, and there are promises that we will shortly ruin the entire country, so long as we are not expensively fixed. Our continued existence, as ourselves, as autistics, is held to be an affront to the whole idea of Canada.

At the same time, autism advocates claim that this impending national catastrophe can be averted if there is unlimited funding for intensive interventions based on applied behaviour analysis, ABA, Lovaas-type or otherwise, for autistics of all ages. ...

Autistic abilities and traits are assumed to be non-existent or destructive, useless, and wrong. There is everything to gain and nothing to lose if our lives are dedicated to striving every minute to be normal, that is, non-autistic. The

²⁵⁶ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁵⁷ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁵⁸ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁵⁹ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*goal of this kind of intervention, Ivar Lovaas has repeatedly written, is to build a person where none exists.*²⁶⁰

Ms. Dawson is of the view that autism is not a mental illness.²⁶¹ She suggests that what is truly needed is “an accurate and unbiased source of information about autism in Canada.”²⁶² In her view, this report is not the appropriate forum for dealing with this issue.

The Committee recognizes that family caregivers are struggling to provide the best care possible for persons living with autism. Their emotional and financial hardships are very real, and a solution must be found. However, we do not believe that the Committee is well placed to make recommendations at this time. Further study is required if we are to do justice to an extraordinarily complex issue where even the most basic question — “is autism a mental illness?” — remains contentious.²⁶³

In its earlier report, *The Health of Canadians — The Federal Role*, the Committee laid out the thematic studies to be investigated in future. We are committed to this work, as evidenced by this study of mental health and addiction. In future, we hope to have the opportunity to undertake a thematic study on autism. Meanwhile, we advocate a fuller debate among all stakeholders. In particular, the Committee believes that persons living with autism must be recognized as full and equal partners in the discussion.

6.6 CONCLUSION

The Committee is deeply concerned about the capability of the mental health system to respond to the needs of children and youth. Fragmentation, coupled with under-funding, a shortage of mental health professionals, and a failure to involve younger people, and their families in long-term treatment solutions, has resulted in the delayed application of inadequate treatment interventions. Simply put, this is unacceptable. A much greater investment in children’s mental health is required if it is to shed its label as the “orphan’s orphan” within the health care system. By using the Committee’s recommendations as a guide to restructure the system on an urgent basis, it is our belief that an investment in early intervention will result in significant long-term savings within the health care system, and beyond.

²⁶⁰ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁶¹ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁶² 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁶³ Both the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, and the International Classification of Diseases, published by the World Health Organization, classify autism as a mental disorder. However, some experts offer an alternate viewpoint. See, for example, Professor Greg O’Brien’s testimony before the UK Parliament, available on-line at <http://www.publications.parliament.uk/pa/jt200405/jtselect/jtment/79/4102708.htm>], and that of Drs. Betty Jo Freeman and Dr. Ritvo (12 Employee Benefits Cases 1221, 19 A.L.R. 5th 1017, 910, F.2d 534 (9th Cir.)), available online at <http://www.geocities.com/fishstep/Kunin.html>.

7.1 INTRODUCTION

When we talk about serious and chronic mental illness, we are not [only] talking about Alzheimer's and dementia, which everybody automatically assumes. We are talking about the older adult and senior who have lived their life with schizophrenia, bipolar disorder, or a personality disorder. Because people are aging, obviously we are going to see that more often. These people are probably the most difficult, the most vulnerable and the most forgotten people that we serve. —Suzanne Crawford²⁶⁴

Today, Canadians have a life expectancy of close to 80 years.²⁶⁵ Increased lifespan, coupled with a declining birth rate, has meant that seniors, aged 65 and over, now represent a large and growing proportion of our population.²⁶⁶ Of these, 20% are living with mental illness.²⁶⁷

Specialized treatment programs and support services for seniors are lacking, as are the research and knowledge exchange necessary for their development and improvement.

Efforts to address deficiencies in existing treatment and support services are consistently hampered by the application of a philosophy of simply “warehousing” those who suffer the disadvantage of being both aged and mentally ill.

While this rate of incidence is comparable to other age groups, it masks alarming problems such as the 80-90% of nursing home residents who are living with mental illness²⁶⁸ or some form of cognitive impairment.²⁶⁹ It also fails to reveal the fact that more elderly seniors are facing particularly acute challenges that include high rates of Alzheimer's disease and related dementias, and for men, a significant incidence of suicide.²⁷⁰

²⁶⁴ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-c/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁶⁵ Statistics Canada. *The Daily*, Demographic statistics. (28 September 2005) <http://www.statcan.ca/Daily/English/050928/d050928a.htm>.

²⁶⁶ By 2016, it is estimated that seniors will represent over 16% of the population, up from 13% today. Penny MacCourt. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 4. By 2026, it is estimated that one in five Canadians will be aged 65 and over, up from one in eight in 2001. Statistics Canada. (2002) *Canada's Aging Population: A report prepared by Health Canada in collaboration with the Interdepartmental Committee on Aging and Seniors Issues*, p. 1.

²⁶⁷ *Ibid.*

²⁶⁸ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 5, Section 5.1.3, p. 88.

²⁶⁹ Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 2.

²⁷⁰ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 5, Section 5.1.3, p. 88.

In the course of its consultations, the Committee identified a series of significant problems that, while particular to seniors, are simultaneously interwoven within the broader failings of the mental health system. Regrettably, the Committee found that for seniors, as for other population groups, the available treatment and support services are, in general, inadequate. More specifically, specialized treatment programs and support services for seniors are lacking, as are the research and knowledge exchange necessary for their development and improvement.

As well, mental health services are often not available to seniors where they live, an important consideration given the limited mobility of this population. In addition, the fact that seniors often shift from community-based to institutional-based care is often not taken into account and planned for, making the transition both troublesome for the person affected and inefficient. Finally, efforts to address deficiencies in existing treatment and support services are consistently hampered by the application of a philosophy of simply “warehousing” those who suffer the disadvantage of being both aged and mentally ill. Sadly there is little focus on the recovery of seniors affected by mental illness.

7.2 SPECIALIZED TREATMENT NEEDS

Seniors are not just older adults whose mental health problems can be addressed within generic treatment programs that are supposedly suited to all ages. They are a demographic segment with unique attributes that distinguish their mental health needs from those of other groups. A participant in the Committee’s on-line consultation described it this way:

...seniors are a distinct group. They deserve strategies, programs and policies that address their particular issues...
—Jennifer Barr

Seniors with chronic mental health problems are a seriously under-served population. They often do not “fit” mental health services/ residential programs developed for adults (they may have physical/functional/cognitive impairments related to aging in addition to their chronic mental health problems), nor do they necessarily “fit” in long term care programs (they may be very physically and functionally well). —Anonymous

This perspective was echoed by Jennifer Barr of the Centre for Addiction and Mental Health, who stated that:

...seniors are a distinct group. They deserve strategies, programs and policies that address their particular issues, as other groups need idiosyncratic programming across the lifespan. We cannot paint everybody with the same brush.²⁷¹

Also, it is important to recognize that seniors are not a homogeneous group. They encompass a broad range of ages, and their mental health needs vary within these age-groups from youngest to oldest.

²⁷¹ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The prevalence of Alzheimer’s disease serves to illustrate this point. It is widely known that Alzheimer’s disproportionately affects seniors. However, while this disease touches 1 in 13 persons over the age of 65, its prevalence increases sharply to 1 in 3 in persons over the age of 85.²⁷²

Mental health service delivery, and the research that ought to underpin it, must take this diversity into account. As Faith Malach, Executive Director of the Canadian Coalition for Seniors’ Mental Health, emphasized in her testimony to the Committee:

*When we talk about “seniors”, I am not sure whether there is an assumption that we are talking about a large range of people.... There are vast differences between 65-year-olds and 95-year-olds, and when we are collecting indicators and looking at statistics, we need to remember that even within the seniors’ population, there is a huge range.*²⁷³

The failure of the mental health system to recognize the uniqueness and diversity of seniors’ needs may be attributed in part to the lack of knowledge exchange amongst researchers in gerontology, as well as between those who provide care to geriatric populations and the broader community of mental health and addiction care providers. Witnesses went so far as to claim that Canadian researchers working in seniors’ mental health “have no idea who each other are,” despite their small numbers.²⁷⁴ The remedy, as Jennifer Barr described it, is that:

*We need to provide gerontology information to mental health and addiction providers. We need to provide mental health and addiction information to gerontology providers. That is putting it very simply. Of course, all this material has to be targeted to the individual setting. Again, it has to be particular to the individuals involved and the particular roles that they play. In terms of knowledge exchange, it has to be complemented by broad public awareness campaigns, and peer and consumer support.*²⁷⁵

Having this in mind, the Committee recommends:

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| 26 | That the Knowledge Exchange Centre to be created as part of the Canadian Mental Health Commission (see Chapter 16) have as one of its goals to foster the sharing of information amongst gerontology researchers themselves, and also between providers of specialist care to seniors and other mental health and addiction care providers. |
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²⁷² Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 5, Section 5.1.3, p. 88.

²⁷³ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁷⁴ Malach, F. 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁷⁵ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

That the Canadian Mental Health Commission encourage research on the broad ranges of ages, environments (i.e., community versus institutional), co-morbidities and cultural issues that have an impact on seniors' mental health, and that it promote best practices in senior-specific mental health programs in order to counter the marginalization of older adults within treatment programs that claim to be suited to all ages.

7.3 LOCATION OF SERVICES

7.3.1 The Reality: A Provider-Driven Model

The mental health system is provider-driven in that it is generally structured to suit primarily the needs of individual and institutional service providers, not their clients. For example, many mental health services are available only in hospitals or other facilities where health service providers are based. Other characteristics of this provider-centric model were described by Charmaine Spencer, Adjunct Professor of Gerontology at Simon Fraser University, who testified that:

The seemingly obvious solution to this dilemma is to provide mental health services where older adults live, be it in their homes, the homes of their caregivers, or in acute care or long-term care facilities.

...they [seniors] are being limited to things such as a 10-minute visit, or ...one visit, one complaint. They see signs that say that. That is not conducive to good mental health service at any level or to any kind of health service for older adults. For older adults in these circumstances, focusing on one issue at a time leads to a crisis-type of approach....²⁷⁶

The challenge posed to seniors by the provider-driven service model varies, depending on their role as caregivers to another family member, their personal financial resources, and the extent to which their mobility is restricted.

Mobility may be impaired by a variety of factors. Individual seniors may not be comfortable driving or may be incapable of doing so. In many communities, public transportation may be poorly designed or simply unavailable, especially outside of urban centres. Even walking may be impeded by poor sidewalk maintenance, particularly in the winter months. Further, even if transportation is available, seniors often have caregiver responsibilities for a spouse or partner that may hamper their ability to leave the home, and they may lack the necessary funds to make use of respite care or to hire a taxi. In short, the service provider-driven model poses significant structural barriers to the use of services by seniors.

²⁷⁶ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

7.3.2 The Ideal: A Client-Driven Mental Health System

The seemingly obvious solution to this dilemma is to provide mental health services where older adults live, be it in their homes, the homes of their caregivers, or in acute care or long-term care facilities. Jennifer Barr put it this way:

...similar to your [the Committee's] recommendation around school-based programming for young people where you want to provide programs that are easily accessible, for example, having an addiction counsellor or a mental health support group in a school setting. Similarly, because older adults are, for a number of reasons, not as likely to reach a treatment service, we need to provide the addiction and mental health services where older adults are found, in all that variety of settings.²⁷⁷

It is not sufficient, however, simply to locate mental health services where seniors live. It is necessary as well to provide a full range of services that are suited to the population in question. As Penny MacCourt noted in her brief, submitted on behalf of the British Columbia Psychogeriatric Association:

For many seniors, the factors that affect their mental health are often related to...deficits in their social support system or environment. Current policy and services...are typically situated within a biopsychosocial model...with an emphasis on the biomedical component. The biomedical model...focuses on individual pathology and leads to the organization of services and programs that focus primarily on the diagnosis and treatment of mental illness. There is a narrow focus on cure and acute care. The biomedical paradigm has led to the neglect of...broader non-medical interventions and community-based services required to support seniors' mental health.²⁷⁸

Thus, services need to be both shifted to the client location and expanded to fit the needs of each particular on-site population. Even once this is done, however, a final step is needed. The gap between the different places in which seniors live must be bridged — that is, the transition of seniors from one location to another over time must be taken into account.

7.3.2.1 Tailoring Services to Where Seniors Live

Life as a senior is often a series of transitions. While some individuals may remain in their homes in comfort until they die, many will shift between their own homes, the homes of family caregivers, acute care and long-term care facilities. The exact details of these transitions are very hard to predict, although we do know that many seniors experience them in some

The Committee believes that, like those with physical health problems, seniors living with mental illness should be provided treatment and support services in their own homes.

²⁷⁷ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁷⁸ MacCourt, P. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 6.

fashion. Seniors may move back and forth between many locations during a period that often extends over three or four decades.

7.3.2.1.1 Seniors Living in Their Own Homes

The Committee believes that, like those with physical health problems, seniors living with mental illness should be provided treatment and support services in their own homes. This should include in-home treatment services by an appropriate mental health service provider and low- or no-cost delivery of medications.

But, as discussed above, the delivery of medical or psychotherapeutic services alone is insufficient. Seniors have additional needs, be they physical (e.g., assistance with the activities of daily living — home maintenance, shopping, cooking, cleaning, or bathing) or social (e.g., visitors or access to library services).

While some recognition has been given to the advantages of maintaining seniors in their own homes, current options are limited. As Terry McCullum, Chief Executive Officer of Leap of Faith, Toronto (LOFI) Community Services, has indicated:

*There are virtually no supportive housing resources if you are an older adult with mental illness and/or addictions.... Your only options are a hospital or a nursing home, but these are expensive, institutional and often not necessary.*²⁷⁹

The near-absence of supportive housing resources is not attributable solely to financial constraints. Instead, as Dr. Martha Donnelly, Head of the Division of Community Geriatrics at Vancouver General Hospital, pointed out:

*...most seniors I meet want to stay in their own home, and that is a good place as long as you can get support services in. The problem is there are sometimes policies that do not allow you to bring in the appropriate support services for mental health clients. For instance, in B.C. [British Columbia] right now we can get homemaking help for people who need help to take a bath. However, if people are suspicious and isolating themselves, we cannot get the homemaking services in. Their physical health is considered important, but not their mental health to the same degree.*²⁸⁰

This should not be the case. The Committee strongly supports the principle that a full range of treatment and support services should be available for *both* the mentally and the physically ill. We also support the creation of affordable (i.e., subsidized) and supportive housing (i.e., housing options where assistance with the activities of daily living is available on-site). Therefore, the Committee recommends:

²⁷⁹ Fine, R. (June 2005) Brief to the Standing Senate Committee on Social Affairs, Science and Technology, Addendum No. 1, p. 1.

²⁸⁰ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

- 27 That money from the Mental Health Transition Fund (see Chapter 16) be made available to the provinces and territories for initiatives designed to facilitate seniors with a mental illness living in the community; these initiatives could include, amongst other things, the provision of:
- home visits by appropriately compensated mental health service providers;
 - a range of practical and social support services delivered in their homes to seniors living with mental illness;
 - a level of support to seniors living with mental illness that is, at a minimum, equivalent to the level of support available to seniors with physical ailments, regardless of where they reside;
 - a more widely available supply of affordable and supportive housing units for seniors living with mental illness.

7.3.2.1.2 Seniors Living With Family Caregivers

The issue of support for family caregivers was examined in Chapter 5. Nonetheless, the Committee believes it necessary to refer here to the particular pressures experienced by those who care for seniors living with mental illness.

Caregiver responsibilities place seniors themselves at risk for mental illness.

First, seniors living with mental illness are often cared for by spouses or partners who are themselves seniors. These caregivers may have their own physical or mental limitations, which place an added strain on the relationship and heighten the need of *both* parties for mental health and support services. As Penny MacCourt pointed out in her submission to the Committee, caregiver responsibilities place seniors themselves at risk for mental illness:

*Caregiving women, especially those caring for an individual with dementia...are at increased risk for depression. Caregivers who receive little social support and who feel burdened and/or lonely are more likely to also experience depression than caregivers with good social support.*²⁸¹

Second, seniors living with mental illness often have many concurrent physical and mental incapacities. As a result, they may demand more of their caregivers than a younger family member might. This reality was described by Karen Henderson in her article entitled “The Dichotomies of Caregiving: Mental Health Challenges of Informal Caregivers.” She wrote that:

Caregivers should not be expected to stand in or substitute for services and supports that should be available to ill family members living alone in their own homes.

²⁸¹ MacCourt, P. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 4.

My caregiving experience taught me that because of the long list of physical and cognitive deficits endured by my father, I ended by adding spouse, parent, personal care aide, friend, chauffeur, decision-maker, advocate, personnel manager, financial manager and funeral planner to my role as daughter. How could anyone fill all these roles and emerge unscathed?²⁸²

Although not a senior herself, eventually the responsibility of caring for an older adult living with mental illness resulted in Ms. Henderson herself becoming clinically depressed.

In addition to recognizing the value of family caregivers and assisting them in that role, steps must be taken to minimize the risk of their developing mental illness. In particular, caregivers should not be expected to stand in or substitute for services and supports that should be available to ill family members living alone in their own homes. Therefore, the Committee recommends:

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| 28 | That seniors with a mental illness who are living with family caregivers be eligible for all of the health and support services that would be available to them if they lived alone in their own home. |
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7.3.2.1.3 Seniors Living in Acute Care and Long Term Care Facilities

Under the service provider-driven model, one might expect seniors to receive appropriate mental health services in the acute care hospitals in which most service providers are based. However, all too often they do not.

Many older adults are being inappropriately “housed” in acute care facilities. The solution lies in making alternatives to hospitalization more widely available.

One reason for this is the widespread perception in acute care facilities that older adults suffering from mental illness should be accommodated in long-term care facilities and thus “spare” the hospital’s limited resources for higher-priority patients.

Dr. Elizabeth Drance, a geriatric psychiatrist, addressed this perception and the consequences for seniors, in her submission to the Committee:

...our frail elders are still considered “bed blockers” and “placement problems” by our acute care environments due to the stresses within the system for beds. The importance of elective admission for geriatric medical and psychiatric assessments, thereby avoiding emergency room admissions, is not well understood by our acute care system caregivers.

²⁸² Henderson, K. (October 2002) The Dichotomies of Caregiving: Mental Health Challenges of Informal Caregivers. In Writings in Gerontology: Mental Health and Aging (National Advisory Council on Aging), No. 18, p. 44.

Many feel that these frail elders do not require admission to hospital at all, and that these beds should be purely utilized only to decant [transfer] patients out of overcrowded emergency rooms. The stress on the acute care system pushes us further away from creating elder-friendly acute care environments, adding to the stress of hospitalization for our frail older adults [and] worsening their mental health.²⁸³

The Committee believes that all Canadians should have access to the acute care system, when and where they need it. There are circumstances where seniors living with mental illness require hospitalization, and this service should be readily available to them. We also recognize, however, that many older adults are being inappropriately “housed” in acute care facilities. The solution lies in making alternatives to hospitalization more widely available.

Today 75 per cent to 85 per cent of the population of personal care homes are persons with cognitive disorders or mental health disorders.

—Annette Osted

...The consequences of this change have not been adequately addressed.

When seniors can no longer be maintained in their own homes or with family caregivers, long term care facilities are often a next step. As Dr. Drance has indicated, however, the need of residents for what she terms “care homes” differs from past years:

...I have seen the population of elders within complex care environments [care homes]...change dramatically over the past 15 years. As more elders stay in their own homes or live in supportive alternatives such as “Assisted Living” environments, the people we are caring for in our care home environments come to us for the following...reasons:

- *Cognitive impairment/Dementia ...*
- *Severe complex physical illnesses with mobility challenges*
- *End of life care*
- *Mixtures of all of the above²⁸⁴*

Her views were echoed by Annette Osted, Executive Director of the College of Registered Psychiatric Nurses of Manitoba, who testified that:

The changes in population in personal care homes must be met with changes to what services are delivered and how. Thirty years ago the population of personal care homes were the physically frail and elderly. Today 75 per cent to 85 per cent of the population of personal care homes are persons with cognitive disorders or mental health disorders.²⁸⁵

²⁸³ Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 1.

²⁸⁴ *Ibid.*, p. 2.

²⁸⁵ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The consequences of this change have not been adequately addressed. There has been an insufficient increase in staffing levels,²⁸⁶ not enough support for upgrading caregiver skill levels,²⁸⁷ and too little enhancement of on-site mental health and support services to meet the increased intensity and modification of care requirements that has been the result of this shift. The end result may be overmedication,²⁸⁸ the use of chemical restraint,²⁸⁹ provision of only the most basic or custodial needs²⁹⁰ — or in short, “warehousing” of our society’s most vulnerable senior citizens.

There are alternatives. Mental health services can be devolved from acute care to long-term care facilities. Support services can be adapted to reflect the shift from physically to mentally frail clients. Committee members who have had a family member living in a long-term care facility described their own experiences with enclosed garden areas employed as an alternative to restraints for persons living with dementia. Attached to long-term care facilities, such areas enable clients to wander freely but safely.

Menna MacIssac, Director of Programs and Operations for the Nova Scotia Alzheimer Society, confirmed that best practices for construction of long-term care facilities have already been established. She pointed to these as “...an opportunity to change the physical and pharmacological environment in which people with dementia are currently living.”²⁹¹

Therefore, the Committee recommends:

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| 29 | <p>That efforts be made to shift seniors with a mental illness from acute care to long-term care facilities, or other appropriate housing, where it is clinically appropriate to do so, by making alternatives to hospitalization more widely available.</p> <p>That staffing competencies in long term care facilities be reviewed and adjusted, through the introduction of appropriate training programs, to ensure that the devolution of responsibility for patients living with a mental illness from acute care facilities to long-term care facilities is done in a way that ensures that clinically appropriate mental health services are available to residents on-site.</p> |
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²⁸⁶ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁸⁷ Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, pp. 2-3.

²⁸⁸ MacIssac, M. 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁸⁹ Osted, A. 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁹⁰ Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 3.

²⁹¹ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

7.3.2.2 Managing the Transition

While it cannot be predicted when people will make the shift from own home, to caregiver home, to hospital, to long-term care facility, what can be affirmed, sadly, is that the transition between these locations will not be seamless. Too often it will be inefficient and inconvenient, at worst it may be unsafe. Dr. Drance described the current situation as follows:

While it cannot be predicted when people will make the shift from own home, to caregiver home, to hospital, to long-term care facility, what can be affirmed, sadly, is that the transition between these locations will not be seamless.

There are many services out there, but right now for a frail senior or their loved one to figure out who to call, where to call, that navigator role is a key one. Family physicians need to be able to navigate the system as well. We have not done a good job of gathering all these services together and helping people access them relatively straightforwardly. It is an incredibly complex system.²⁹²

There are a number of potential solutions to this problem. First, resources can be invested to help seniors and their family caregivers better navigate the existing system through the use, for example, of professional system navigators. Second, there can be greater centralization of transitional services in traditional locations, i.e., where service providers are currently based (pending implementation of the reforms recommended above). Third, services can be shifted to centralized locations, such as long-term care facilities, where many seniors live.

The Committee believes that the last option would provide the most benefit. However, we suggest that it be taken one step further. In addition to centralizing services in locations where many seniors live, we are of the view that different “homes” for seniors should be put in close proximity to one another, perhaps even under one roof. Menna MacIssac described one such alternative:

There are facilities now, and we have one here in Capital [Capital Health — Halifax, Nova Scotia] called Northwood, which have an array of services and housing options under the same facility so that as people's needs change — and I am not talking about necessarily dementia, but about a person who has care needs — they can progress through different options. That should be looked to as well.²⁹³

This model has the advantage of addressing simultaneously problems associated with mobility and with making the transition from one housing setting to another. It also would accommodate situations in which aged couples with different care needs can continue to live in the different settings most appropriate to their needs but still be in close proximity to one another.

²⁹² 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁹³ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Therefore the Committee recommends:

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| 30 | <p>That a range of institutionally based services for seniors living with a mental illness be integrated (e.g., supportive housing units and long-term care facilities) by locating them adjacent to each other, to make the transition(s) between different institutional settings efficient and safe.</p> <p>That every effort be made to facilitate aged couples being able to continue to live together, or in close proximity to one another, regardless of the level of services and supports that they each may require.</p> |
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7.4 THE DOUBLE-WHAMMY OF MENTAL ILLNESS AND AGING

The Committee heard that mental health and support services for seniors are falling short of meeting real needs. The question is why? Having reviewed all of the evidence, we concluded that Robena Sirett, Manager of Older Persons Adult Mental Health Services for the Vancouver Coastal Health Association, was right when she stated that:

I would like us to look at is strategies for eliminating the stigma of the double-whammy of...mental illness and aging. Both are very powerful stigmas, and together they influence the care that people seek and receive.

—Robena Sirett

*A second...area that I would like us to look at is strategies for eliminating the stigma of the double-whammy of...mental illness and aging. Both are very powerful stigmas, and together they influence the care that people seek and receive.*²⁹⁴

Stigma can be subtle, as in the tendency to consider young adults as the norm for all age groups,²⁹⁵ thereby justifying the exclusion of seniors from mental health guidelines²⁹⁶ and negating the need for specialized treatment programs. It can also be more overt, as in the tendency to locate mental health and support services in locations that are inaccessible to those with physical or mental incapacities.

Stigma finds expression in the sense of fatalism that too often infects society's attitude toward seniors. Their symptoms of distress are often dismissed as attributable to "just getting old" or "indulging in a last pleasure." Too often seniors are considered a burden, a drain on scarce resources better invested in younger people with greater potential.

²⁹⁴ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁹⁵ Spencer, C. 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁹⁶ MacCourt, P. 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Stigma is also reflected in the conditions in which many older adults living with mental illness are expected to exist, where hope of recovery is abandoned to overmedication, restraint, and provision of only the most basic custodial needs. The “warehousing” of many, many seniors, as cheaply as possible, is perhaps the ugliest expression of an attitude that does not acknowledge the worth of older people living with mental illness.

As described elsewhere in this report, one of the primary mandates of the proposed Canadian Mental Health Commission will be to launch an aggressive ten-year anti-stigma campaign. A critical objective of that campaign must be to change public attitudes toward seniors who are living with mental illness.

7.5 CONCLUSION

A number of the Committee’s members are themselves older adults. It is our hope that by drawing attention to the shortcomings in the mental health system that affect seniors, and providing recommendations for change and improvement, our own futures, and those of our children and grandchildren, will be more secure. In moving forward, we draw inspiration from seniors themselves who, to quote Charmaine Spencer, have pointed out that:

...in their lifetime they have seen other matters that were previously stigmatized, hidden and never talked about, such as cancer, divorce, pregnancy, and developmental disabilities, become normalized through information, education, and social change. They ask why that is not possible here too.²⁹⁷

The Committee hopes that the work of the Canadian Mental Health Commission will help to make that “normalization” possible as well.

²⁹⁷ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

CHAPTER 8: WORKPLACE AND EMPLOYMENT

It is in the workplace that the human and the economic dimensions of mental health and mental illness come together most evidently. On the one hand, the workplace can contribute positively to mental well-being — it is where we derive a good part of our sense of social integration. As Merv Gilbert, a psychologist at the Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, University of British Columbia, told the Committee:

Work has also been found to play an important role in recovery from mental illness.

*Work provides a sense of structure, social meaning, social supports, a place to go outside the home...and it also provides an income, which we do know is good for your mental health.*²⁹⁸

Work has also been found to play an important role in recovery from mental illness. Employment decreases the rate and duration of hospitalization and enhances quality of life. Surveys show that most persons living with serious mental illness want to work and see employment as a primary goal.

Unemployment for persons living with serious mental illness is estimated to be as high as 90%.

But few are employed. In fact, unemployment for persons living with serious mental illness is estimated to be as high as 90%.²⁹⁹ In addition to unemployment, exclusion from the workforce often results in dependency on income security programs for survival. Unemployment leads to impoverishment and reduced social engagement, which in turn may worsen mental and physical illnesses. It also contributes to feelings of worthlessness and depression, and can lead to substance abuse.

While participation in the workforce can contribute positively to mental health it can also contribute to the development of mental health problems, including stress, depression and anxiety. Mr. Gilbert added that:

*Therein we have one of the fundamental paradoxes we face today: Work is good for your mental health and work can make you crazy.*³⁰⁰

The issues surrounding mental health and the workplace are complex and multifaceted. As professor Romaine Malenfant from the Université du Québec en Outaouais told the Committee:

²⁹⁸ 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

²⁹⁹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.1, p. 107.

³⁰⁰ 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

*Research increasingly shows that we must not only counter the lack of work, or unemployment, in preserving mental health, but also preserve the quality of work so that work plays its full role in building identity and enabling people to achieve their full potential.*³⁰¹

8.1 UNDERSTANDING THE HUMAN COSTS OF MENTAL ILLNESS IN THE WORKPLACE

8.1.1 The Many Factors That Contribute to the Development of Mental Illness

Exploring the complex relationship between work and mental health, professor Marc Corbière, from the Institute of Health Promotion Research, University of British Columbia, told the Committee:

*...it is not always possible to establish a causal relationship between mental health problems and the workplace. Sometimes, factors stemming from both work and outside of work can explain the occurrence of mental health problems.*³⁰²

In a recent article, “Nature and Prevalence of Mental Illness in the Workplace,” Carolyn Dewa and colleagues point out that:

The picture of mental illness in the workplace is becoming increasingly complicated. It is clear that there is a link between mental illness among workers and work-related stress. In turn, both of these are likely to be related to occupation, the work environment and the sex of the worker.

There is also evidence of an association between mental illness and physical disorders. Yet, few studies have considered how all these various factors interact to affect the prevalence of mental disorders among workers. Even fewer have considered their relative contributions to disability in the workplace.³⁰³

The authors note that many factors contribute to the development of mental illnesses such as depression, but that no one really knows as yet how they all interact:

Yet, the most advanced etiological models of adult depression include factors related to genetic vulnerability, as well as developmental factors, neurobiological factors, childhood experiences, life

³⁰¹ 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁰² 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁰³ Dewa, C. S., Lesage, A., Goering, P., and Caveen, M. (2004) Discussion Paper: Nature and Prevalence of Mental Illness in the Workplace. *HealthcarePapers*, Vol. 5, No. 2, p. 18.

events, chronic situations (e.g., a stressful work environment) and the presence of other disorders. ...It is not yet understood what the due weight of each of these factors is and how they fit together.³⁰⁴

There are many ways of classifying the risk factors that contribute to the development of mental illness. In her testimony to the Committee, Lucie France Dagenais, researcher for the Commission des droits de la personne et des droits de la jeunesse in Quebec, identified two broad categories of risk factor:

*The first are those related to social relations in the workplace. This includes violence, harassment, lack of social support and poor work relations. The second category includes those found in the work organization, which are much less known on an analytical basis. We identified work intensification, lack of flexibility, non-standard work schedules, lack of recognition, lack of expression groups, advancement on the basis of merit and flexibility.*³⁰⁵

However, as Michel Vézina and colleagues point out in a recent article, “there is a regrettable absence of scientific consensus on how to define and measure a high-risk psychosocial work environment.” These authors define “psychosocial factors” as those that “refer to all organizational

There is a regrettable absence of scientific consensus on how to define and measure a high-risk psychosocial work environment.

— **Michel Vézina**

factors and interpersonal relationships in the workplace that may impact health.” Among the factors that “make it possible to document the stressful nature of a work situation” they list:

...control (latitude, participation, use and development of skills), workload (quantity, complexity and time pressures), roles (conflict and ambiguity), interpersonal relationships (social support, harassment and recognition), career prospects (promotion, precariousness and demotion), organizational climate or culture (communication, hierarchical structure and fairness) and the interaction between work and private life.³⁰⁶

Negative attitudes towards mental illness remain widespread throughout society and can compound the difficulties generated by conditions in the workplace. Employers and co-workers may fear people living with a mental disorder; they may think of persons with mental illness as unskilled, unproductive, unreliable, even potentially violent.³⁰⁷ These unwarranted perceptions may contribute to a reluctance to hire someone with a history of mental illness, or to limit that individual’s career advancement if a previously undisclosed mental illness is revealed. Job loss is also a possible danger for those with the courage to “come out” of the closet at work.

³⁰⁴ *Ibid.*, p. 20.

³⁰⁵ 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁰⁶ Vézina, M., Bourbonnais, R., Brisson, C., and Trudel, L. (2004) Discussion Paper: Workplace Prevention and Promotion Strategies. *HealthcarePapers*, Vol. 5, No. 2, p. 34.

³⁰⁷ Canadian Psychiatric Association. (2005) *Mental Illness and Work*. <http://www.cpa-apc.org/MIAW/pamphlets/Work.asp>.

It is important to recognize that this lack of understanding of the relationship between work and mental illness is not only an issue inside the workplace; it extends also to health professionals. Merv Gilbert told the Committee:

*Most mental health providers do not have a clue — I say respectfully — about what goes on in the workplace. Typical GPs faced with a patient coming in tears with a diagnosable disorder and being asked to make decisions about whether or not to stay at work, to return to work, how to deal with workplace issues, often are poorly informed. They may have a poorly written job description in front of them, if they are lucky, on which to make a determination as to whether that person should be at work, how the individual should be accommodated and what kinds of issues should be addressed. Therefore, I strongly suggest we need to educate the health care system as well.*³⁰⁸

It is important to recognize that this lack of understanding of the relationship between work and mental illness is not only an issue inside the workplace; it extends also to health professionals.

8.1.2 The Episodic Nature of Mental Illness

The episodic and cyclical nature of most mental illnesses is another factor that makes it harder to assess the impact of mental illness in the workplace. It creates additional difficulties in making the necessary accommodations at work for people living with mental illness. Unlike other disability groups, people with mental illness are rarely ill continuously; rather, they tend to cycle between periods of illness and wellness. When they are symptom-free, they are usually able to work and carry out the normal tasks of life. During episodes of psychiatric illness, however, they may be incapable of functioning at a level that would permit them to work in regular, full-time employment.

The episodic and cyclical nature of most mental illnesses is another factor that makes it harder to assess the impact of mental illness in the workplace.

The cyclical, episodic, and unpredictable nature of serious mental illness can impede the establishment of a long-term and stable employment history. Having unexplained work-gaps on one's resumé poses a formidable challenge when seeking to return to employment.

8.1.3 The Varying Nature of the Relationship Between Mental Illness and Work

People fall into a number of different categories, each of which confronts its own particular challenges with respect to employment-related mental health issues.

In many cases, the onset of a mental disorder occurs in late adolescence or early adulthood, at a time when the affected person's education and training are not yet complete.³⁰⁹ The process of obtaining qualifications can be interrupted, often never to be resumed. Young individuals in this category are significantly disadvantaged; their lack of skills and qualifications constitute a major and lifelong barrier to future employment.

³⁰⁸ 5 July 2005, <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report1/repintnov04vol1-e.pdf>.

³⁰⁹ See Chapter 6, Children and Youth.

For others, their careers may be disrupted by serious mental illness or addiction. Many never regain their foothold in the marketplace. For those who do find work, the periods outside the labour force caused by their mental illness often hinder their re-entry.

Three key barriers apply. First, individuals may be subject to discrimination by their employer and/or co-workers. Second, to cope with their illness they may require flexible work arrangements that employers are unwilling, or do not know how to provide. And third, those who have been outside the labour force for extended periods are unlikely to have the type of credentials, skills and employment experience that make them attractive to employers.

Finally, there is the broad category of people who are currently employed but whose productivity is affected to varying degrees by mental health difficulties, a state often referred to as “presenteeism.”

This diversity means that the issue of mental illness, addiction and work has to be explored from a number of different perspectives: making employment accessible to individuals who have never had a job; enabling individuals who have lost their job due to mental illness or addiction to reintegrate into the labour market; and studying how mental illness and addiction affects currently employed individuals.

8.1.4 Many Unanswered Research Questions

A review of current research illuminates how little is known about work-based mental illness and stress-related disorders, in terms either of defining the scope of the problem or establishing best practices to manage it.³¹⁰ In a recent article, Elliot Goldner and colleagues note that:

A review of current research illuminates how little is known about work-based mental illness and stress-related disorders, in terms either of defining the scope of the problem or establishing best practices to manage it

There has been significant research activity on workplace health that has considered disability management, return to work and treatment. For the most part, however, such research has not directly addressed mental health problems or mental illness but have been focused upon various physical health problems encountered in the workplace (e.g., back injury and other musculoskeletal problems, brain injury, cardiac illness and chronic rheumatic diseases).³¹¹

They also point out that the paucity of research into mental health at work is not a new phenomenon:

³¹⁰ Archambault, E., Cote, G., and Gingras, Y. (2003) Bibliometric Analysis of Research on Mental Health in the Workplace in Canada. Cited in research conducted for the Committee by Neasa M. Martin and Associates, June 2005.

³¹¹ Goldner, E., Bilsker, D., Gilbert, M., Myette, L., Corbiere, M., and Dewa, C. S. (2004) Discussion Paper: Disability Management, Return to Work and Treatment. *Healthcare Papers*, Vol. 5, No. 2, p. 77.

In an article in 1993, Rachel Jenkins asked why mental health at work was so under-researched. More than a decade later, the same question remains relevant. There are many gaps in knowledge to be filled. Little is known regarding best practices in managing the disability associated with the most prevalent mental disorders (i.e., depression, anxiety disorders and substance use disorders). Although some information is available to assist people with severe mental disorders in obtaining employment, knowledge to help people maintain employment is lacking. Additionally, knowledge regarding systemic factors that influence disability management and return to work (e.g., employee assistance programs and disability insurance regulations) relevant to people with mental disorders is yet unavailable.³¹²

Importantly, a further barrier to integrated research into mental health at work originates in the fact that specialists in different fields do not always speak the same “language.” This point is well made by Aldred H. Neufeldt:

A major challenge is that much existing knowledge is subject to what might be called an “isolated pockets syndrome.” The different kinds of research...are published in different types of journal, with cross-referencing infrequent. Epidemiological journals examine the relationship between functioning and psychiatric impairment. Occupational psychology and health literature examines topics such as workplace stressors, health, performance and absenteeism. Literature on rehabilitation and psychiatric fields examines specific treatments for psychiatric conditions, along with the effectiveness of interventions such as short- versus longer-hospital stays, supported employment, case management and others.³¹³

For employers and employees alike this “language” diversity makes it even harder to establish best practices derived from full reviews of the scientific literature.

8.2 THE ECONOMIC IMPACT OF MENTAL ILLNESS IN THE WORKPLACE

To repeat, there are many important gaps in the research into mental health in the workplace. In its interim report, the Committee noted the absence of definitive statistics on the prevalence of mental illness and addiction in the workplace.³¹⁴

³¹² *Ibid.*, p. 86.

³¹³ Neufeldt, A. H. (2004) Discussion Paper: What Does It Take to Transform Mental Health Knowledge into Workplace Practice? Towards a Theory of Action. *Healthcare Papers*, Vol. 5, No. 2, p. 123.

³¹⁴ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.1, p. 107. See also Dewa et al. (2004), p. 13.

Nonetheless, the Committee was informed that disability claims attributable to mental illness have overtaken claims associated with cardiovascular disease as the fastest-growing category of disability costs in Canada. Currently, mental illness and addiction account for 60-65% of all disability insurance claims among selected Canadian and American employers.³¹⁵

Dewa and colleagues report that:

Over the last few years, the number of disability claims for mental disorders has been soaring. Between 1989 and 1994, according to the Health Insurance Association of America (1995), such claims doubled. In Canada, short- and long-term disability related to mental illness accounts for up to a third of claims and about 70% of the total costs — \$15 to \$33 billion annually.³¹⁶

Disability claims attributable to mental illness have overtaken claims associated with cardiovascular disease as the fastest-growing category of disability costs in Canada. Currently, mental illness and addiction account for 60-65% of all disability insurance claims among selected Canadian and American employers.

When compared to all other diseases (such as cancer and heart disease), mental illness and addiction rank first and second in terms of causing disability in Canada, the United States and Western Europe. Of the ten leading causes of disability worldwide, five are mental disorders: unipolar depression, alcohol use disorder, bipolar affective disorder, schizophrenia and obsessive-compulsive disorder.³¹⁷

Mental illness and addiction rank first and second in terms of causing disability in Canada, the United States and Western Europe.

Moreover, as the Global Business and Economic Roundtable on Addiction and Mental Health has pointed out, mental illnesses — depression, anxiety disorders and substance abuse — are concentrated among men and women in their prime working years and among people aged 15 to 24.³¹⁸ Those Canadians most likely to experience a mental illness are amongst those at the heart of our working and consuming population.

Mental disorders, unchecked and disabling, impair the capacity of a significant segment of our population to contribute actively to the economy. Innovation and productivity are increasingly key to economic growth and prosperity. Mental disorders should be recognized as a leading source of disability among those we rely on to wield these critical levers of growth and competitiveness.

³¹⁵ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.4, p. 113.

³¹⁶ Dewa et al. (2004), p. 22.

³¹⁷ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.3, p. 110.

³¹⁸ Global Business and Economic Roundtable on Addiction and Mental Health. (2006) Employers Getting Started — The Road to Mental Health and Productivity, Module Three: The Demographics and Distribution of Mental Illness: Mostly an Economic, Business and Labour Cost — Health Care Costs Less Than Productivity Loss.

Productivity is affected both by “presenteeism” — days during which an individual is present at work but functions at less than full capacity — and by absenteeism — days during which an employee did not report to work. Mental illness and addiction are among the most important causes of absenteeism and presenteeism worldwide: a 1998 report of the World Health Organization observed that “more working days are lost as a result of mental disorders than physical conditions.”

In Canada, 20% of the normal work time of employees suffering from an undetected mental illness or addiction is not productive because it is “taken off.” Absenteeism at this rate is four times the rate of unaffected co-workers.³¹⁹

Those Canadians most likely to experience a mental illness are amongst those at the heart of our working and consuming population.

Dewa and colleagues point out that:

It has been observed that a significant proportion of the burden of mental disorders arises from presenteeism days...This disability pattern distinguishes mental disorders from chronic physical conditions. Chronic physical conditions are associated with total disability days, while the predominant effect of psychiatric disorders is on partial disability; in fact, psychiatric disorders were responsible for 23 times as many partial disability days as total disability days.³²⁰

The value of lost productivity in Canada that is attributable to mental illness alone has been estimated at some \$8.1 billion in 1998. More recently, if substance abuse is taken into account as well, that estimate grows to a loss to the economy of some \$33 billion annually. This corresponds to 19% of the combined corporate profits of all Canadian companies, or 4% of the national debt.³²¹

The costs of mental disorders in the labour force in Canada fall mostly on employers and employees through their payment of operational, payroll, premiums and out-of-pocket expenses. In statements made to the Global Business and Economic Roundtable on Addiction and Mental Health,³²² a number of major Canadian companies have indicated the extent of the costs of mental disorders in their workforces:

- At CIBC, mental disorders produced absences averaging 95 days, compared to 40 days for other illnesses.

³¹⁹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.3, p. 110.

³²⁰ Dewa et al. (2004), p. 19.

³²¹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.3, pp. 110-111.

³²² Global Business and Economic Roundtable on Addiction and Mental Health. (2006) Module Three.

- Great-West Life Assurance Company estimates that 30% of disability insurance claims relate to mental illnesses, and in the remaining 70%, a quarter or more have mental illnesses as a secondary or underlying diagnosis.

8.2.1 The Impact of Global Economic Trends on Mental Health Issues in the Workplace

Two trends, both highlighted by the Global Business and Economic Roundtable on Addiction and Mental Health, are of great significance for how mental health issues in the workplace must be addressed in the 21st century.³²³

If it is true (as it almost certainly is) that we are in the midst of the emergence of a brain-based economy, mental health issues must now become front and centre in the economic affairs of Canada.

The first — the growing importance of knowledge, and of brain-based skill sets generally, to economic performance — provides a major positive incentive to address mental health issues in the workplace.

The second — the demands imposed by an investment-driven, globally competitive economy — reinforces the first trend in many ways, but it can also be the source of significant risk factors for mental illness in the workplace, in particular by increasing the level of stress placed on employees.

Most new jobs today demand brain-based (cerebral) skills and not the manual ones that were so important to previous generations. If it is true (as it almost certainly is) that we are in the midst of the emergence of a brain-based economy, mental health issues must now become front and centre in the economic affairs of Canada.

This new reality is increasingly recognized at the highest levels of corporate Canada. Gordon Nixon, President and CEO, RBC Financial Group, has been quoted as saying that “this is an economy of mental performance and this defines the capacity of employees to be innovative — to think — a key asset.” Robert MacLellan, Executive Vice-President and Chief Investment Officer of the TD Bank Financial Group, has pointed to the importance of mental health in this context: “High rates of mental illness (brain-based disorders) rob our economy of employee capacity to be productive, innovative.”³²⁴

The Honourable Michael Wilson, former special advisor to the Health Minister on mental health in the federal government workplace, has formulated what the Global Business and Economic Roundtable on Addiction and Mental Health calls “The Wilson Principle”:

We have seen tremendous progress in preventing physical injuries and illnesses at work. The safety records of companies I am associated with are a source of great pride to them. I strongly encourage employers to build on these achievements.

³²³ Global Business and Economic Roundtable on Addiction and Mental Health. (2006) *Employers Getting Started — The Road to Mental Health and Productivity, Module Two: The Building Blocks of Productive Capacity in a Brain-Based Economy — Setting the Stage for Mental Health in the Workplace.*

³²⁴ *Ibid.*

It would be a shame to un-do 30 years of great progress in physical health and safety as a result of massive losses of productive capacity due to untreated mental illness in the workplace, especially depression.³²⁵

Evolution of the economy has thus produced a new and costly convergence — the advent of a brain-based economy at the same time that brain-based disorders are becoming the principal cause of disability in the labour force.

Evolution of the economy has thus produced a new and costly convergence — the advent of a brain-based economy at the same time that brain-based disorders are becoming the principal cause of disability in the labour force.

However, the implications of this new reality are not always immediately apparent, especially given the second trend mentioned above. The tendency for business to face intense pressure, especially from investors, to maximize shareholder value has led some companies to lay people off, and to struggle to “do more with less.” Beyond the tremendous human costs for the people involved in massive corporate downsizing, it is also important to recognize the possible longer-term consequences of this strategy for the enterprises themselves.

There is thus a strong and compelling business case to be made for making the workplace an environment that is conducive to mental health.

In an economy that puts a premium on workplace productivity and innovation, the prudent deployment of human capital is critical to competitive success. Human capital is really productive capacity. In an economy based on the mental performance of employees, the capacity to think, concentrate and innovate is critical. Strategies that undermine this capacity are likely to have detrimental effects on the long-term interests of the corporations that engage in them.

There is thus a strong and compelling business case to be made for making the workplace an environment that is conducive to mental health, since the payback in greater productivity will outweigh the costs of the investment required to significantly reduce mental health risk factors in the workplace.

8.3 WORKPLACE-BASED INITIATIVES

There are two broad categories of mental health intervention in the workplace. First, primary prevention measures aim to eliminate, or at least reduce, factors in the workplace that have a negative impact on the mental health of the workforce. Second, there is a range of secondary intervention strategies designed principally to reduce the effects of stressful work situations by improving the ability of individuals to adapt to and to manage stress.

Preventative intervention research identifies work-related causes that must be addressed in order to reduce or eliminate stress.

³²⁵ *Ibid.*

8.3.1 Primary Prevention

There is evidence to indicate that well-structured organizational approaches generate more important, longer-lasting effects than secondary intervention strategies directed at individuals.³²⁶ Preventative intervention research identifies work-related causes that must be addressed in order to reduce or eliminate stress. Two risk models identify those psychosocial and interpersonal relationship factors that contribute to making people sick: 1) Karasek's "job demand-control-support" and 2) Siegrist's "effort/reward imbalance" models.

The "job demand-control-support" model is based on the finding that a work situation characterized by a combination of high psychological demands and low decision latitude increases the risk of developing physical and mental health conditions.³²⁷ The

Interventions focused on organization of work can have considerable benefits, notably decreased absenteeism and symptoms of depression, and even increased well-being and productivity.

"effort/reward imbalance" model is based on the finding that a work situation characterized by a combination of high effort and low reward can be accompanied by emotional and physiological reactions that can have a negative impact on mental health.³²⁸

While "control" is central to the Karasek model, "social reciprocity" (i.e., the possibility of having access to legitimate advantages, duly earned in the process of performing the work) is the key concept for Siegrist's model. Siegrist's model is particularly well adapted to measuring the impact on mental health of a major characteristic of workplace changes in the past decade, namely, reduced security of employment.³²⁹

Various studies have identified workplace attributes that contribute both to profitability and to better mental health, including: employment security, self-managed teams and decentralized decision-making, extensive training, reduced status distinctions, and reduced barriers to sharing financial and performance information across the organization. Vézina and his colleagues refer to studies that identify five factors that are necessary for the success of a primary intervention project. They are:

...support from senior management and involvement of all of the hierarchy; employee participation in discussions of problems and possible solutions; preliminary identification of worker populations at risk on the basis of validated theoretical models or their associated manifestations; rigorous implementation of necessary changes in targeted worker populations; on-site management of the procedure and changes.³³⁰

Studies have shown that if those factors are in place, interventions focused on organization of work can have considerable benefits, notably decreased absenteeism and symptoms of depression, and even increased well-being and productivity. Despite this empirical evidence

³²⁶ Vézina et al. (2004), p. 39.

³²⁷ *Ibid.*, p. 34.

³²⁸ *Ibid.*, p. 36

³²⁹ *Ibid.*

³³⁰ Vézina et al. (2004), pp. 39-40.

to support the health impact of these models, however, few comprehensive workplace intervention strategies have been implemented.

The Global Business and Economic Roundtable on Addiction and Mental Health has identified 10 management practices or behaviours that can precipitate or aggravate mental health problems in the workforce:

1. Imposing unreasonable demands on subordinates and withholding information materially important to them in carrying out their jobs.
2. Refusing to give employees reasonable discretion over the day-to-day means and methods of their work.
3. Failing to credit or acknowledge their contributions and achievements.
4. Creating a treadmill at work — too much to do, all at once, all the time.
5. Creating perpetual doubt, employees never sure of what’s happening around them.
6. Allowing mistrust to take root. Vicious office politics disrupt positive behaviour.
7. Tolerating, even fostering, unclear company direction and policies, job ambiguity and unclear expectations.
8. Sub-par performance management practices — specifically employee performance reviews — even good ones — which fail to establish the employee’s role in the company’s near or mid-term future.
9. Lack of two-way communication up and down the organization.
10. Managers rejecting, out of hand, an employee’s concerns about workload.³³¹

The Committee agrees with the Roundtable that a successful primary intervention strategy must attempt to modify these unhelpful practices, and therefore recommends:

| | |
|-----------|--|
| 31 | That the Canadian Mental Health Commission (see Chapter 16) work with employers to develop and publicize best management practices to encourage mental health in the workplace. |
|-----------|--|

³³¹ Global Business and Economic Roundtable on Addiction and Mental Health. (2004) Roundtable Roadmap to Mental Disability Management.

8.3.2 Secondary Intervention

Three types of secondary intervention are of particular importance: (1) disability management; (2) workplace accommodations; and (3) Employee Assistance Programs (EAPs).

8.3.2.1 Disability Management

Workplace disability management is widely used to return people with physical disabilities to the workplace. Factors found to enhance return to work are: employer participation, a supportive work climate, and cooperation between labour and management. Although widely practiced in association with physical conditions, disability management programs are relatively new to the mental health field and are too little studied to determine their effectiveness.³³²

The lack of “mental illness literacy” amongst employees, managers and supervisors also reduces the likelihood of speedy identification and resolution of mental health and addictions problems in the workplace.

Managing disability within the workplace can be complex, given that it is a shared responsibility of the worker, supervisors and managers, employee assistance programs, human resource managers, and the public health system.³³³ The lack of “mental illness literacy” amongst employees, managers and supervisors also reduces the likelihood of speedy identification and resolution of mental health and addictions problems in the workplace.

A further challenge stems from the fact that the health care system and the workplace are very different, with differing cultures, languages, practices and priorities. The differing conceptual frameworks used by mental health and occupational health professionals can create gaps in understanding, that can lead to a poor coordination of services and result in delays in returning people to work.³³⁴ Creating common goals, a shared understanding and a common language that will allow information to be shared and knowledge to be conveyed across different systems is essential. What is needed are boundary walkers — leaders who are versed in both mental health and employer issues and who can help to integrate disparate systems more effectively over time.

The Committee therefore recommends:

³³² Neufeldt (2004).

³³³ Gnam, W. (2004) Researcher Response: Research Priorities Are Critical. *HealthcarePapers*, Vol. 5, No. 2, pp. 91-94.

³³⁴ Bender, A., and Kennedy, S. (2004) Discussion Paper: Mental Health and Mental Illness in the Workplace: Diagnostic and Treatment Issues. *HealthcarePapers*, Vol. 5, No. 2, pp. 54-67.

32 That the Knowledge Exchange Centre to be created as part of the Canadian Mental Health Commission (see Chapter 16) assist employers, occupational health professionals and mental health care providers in developing a common language for fostering the management of mental illness in the workplace and in sharing best practices in this area.

8.3.2.2 Workplace Accommodations

Accommodation refers to “any modification of the workplace, or in the workplace procedures, that makes it possible for a person with special needs to do a job.”³³⁵ Just as individuals with physical disabilities may require physical aids or structural changes to the workplace, individuals with mental disorders most often require social and organizational accommodations to be made.

Accommodation means providing equitable treatment for individuals with disabilities, regardless of their type and source.

Generally these involve changes to the way things have traditionally been done in a particular workplace. Permitting someone with a mental illness to work flexible hours, for example, provides him or her access to employment in the same way a ramp does for an individual in a wheelchair. Accommodation means, in effect, providing equitable treatment for individuals with disabilities, regardless of their type and source.

There is no comprehensive list of the accommodations needed by people who are dealing with mental health issues, nor is there research that defines “best practice” approaches.

According to the Canadian Psychiatric Association,³³⁶ accommodation should be built on positive arrangements that promote equality in employment, including:

- Creating an environment in which arrangements are made in relation to the individual needs of each employee;
- Respecting the employee’s desire for confidentiality as well as identifying the specific form and the degree of confidentiality required;
- Being willing to engage in joint problem solving;
- Making all arrangements voluntary for the employee, and being prepared to review plans periodically to meet changing needs;

³³⁵ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.5.2, p. 123.

³³⁶ *Ibid.*, p. 124.

- Being flexible in enforcing traditional policies;
- Being concrete and specific when identifying accommodations that are made. Putting them in writing is a good idea.

One study followed 240 persons with serious mental illnesses over a 10-year period who were able to maintain gainful employment, largely because formal work reintegration programs were in effect. These individuals earned \$5 million, paid \$1.3 million in income taxes, and saved the government an estimated \$700,000 in welfare costs. The result was a net \$2-million increase in collective wealth.³³⁷

There is no comprehensive list of the accommodations needed by people who are dealing with mental health issues, nor is there research that defines “best practice” approaches.

According to Mental Health Works, CMHA Ontario,³³⁸ there is no comprehensive list of the accommodations needed by people who are dealing with mental health issues, nor is there research that defines “best practice” approaches. Accommodation requires consideration of the individual needs of employees and the resources available to the employer. In any case, as systemic barriers are removed, the need for individual accommodation will decrease. For example, flextime programs can benefit all employees, while also allowing an employee with a mental illness who needs to modify his or her hours of work to do so without having to ask for any special further accommodation to be made.

The duty to accommodate is not the employer’s alone — trade unions share this responsibility. In the Committee’s view, the interests of the employee are best served when management and unions work cooperatively in accommodating the return to work through job modifications and other such arrangements. In this context, it is important for all

It is important for all parties to remind themselves that the return to work process is, in effect, part of the recovery process for employees living with a mental disorder.

parties to remind themselves that the return to work process is, in effect, part of the recovery process for employees living with a mental disorder.

8.3.2.2.1 Other Mental Health Accommodations

Other possible mental health accommodations include the following.

Flexible scheduling

- Part-time shifts (which may be used to return a worker to a full-time position).
- More frequent breaks.

³³⁷ Harnois, G., and Gabriel, P. (2000) *Mental Health and Work: Impact, Issues and Good Practices*. Joint publication of the World Health Organization and the International Labour Organization, Geneva, p. 19.

³³⁸ Mental Health Works, CMHA Ontario. <http://www.mentalhealthworks.ca/index.asp>.

Changes in supervision

- Modifying the way instructions and feedback are given. For example, written instructions may help an employee focus on tasks.
- Having weekly meetings between the supervisor and employee may help to deal with problems before they become serious.

Changes in training

- Allowing extra time to learn tasks.
- Allowing the person to attend training courses that are individualized.

Modifying job duties

- Exchanging minor tasks with other employees.

Modifying work space or changing location

- Allowing an employee to relocate to a quieter area where he or she will be free from distractions.
- Allowing an employee to work at home.

8.3.2.3 Employee Assistance Programs (EAPs)³³⁹

EAPs are employer-sponsored programs designed to alleviate and assist in eliminating a variety of workplace problems. The source of these problems can be either personal (legal, financial, marital or family-related, mental health problems and illnesses, including addiction) or work-related (conflict on the job, harassment, violence, stress, etc.).

EAPs have become the primary portal through which working Canadians often get their first access to mental health care and addiction treatment.

Typically, EAPs provide counselling, diagnostic, referral and treatment services. Those staffing EAP programs usually hold a degree in a mental health or social service discipline (social work, psychology, psychiatry, counselling and/or marital and family therapy). Some services may also be contracted out to qualified persons.

EAP services are available both in private and public organizations and are usually administered completely independently of other programs within the organization. Confidentiality is the cornerstone of an effective EAP. The anonymity of clients, the confidentiality of interviews, the maintenance, transfer and destruction of files are subject to applicable federal and provincial laws that define the conduct of counsellors. Generally,

³³⁹ This section is drawn largely from: Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, pp. 121-23.

information may be released by an EAP counsellor only in situations in which the client has provided informed and signed consent specifying what information is to be released and to whom.

The Committee was told that between 60% and 80% of Canadians who are employed in a medium-sized or large company (over 500 employees) currently have access to some form of EAP. According to Rod Phillips, President and CEO, Warren Shepell Consultants Corporation, EAPs are very effective; they have become the primary portal through which working Canadians often get their first access to mental health care and addiction treatment:

In many cases, in our experience, you would have about 85 per cent of the people who we see in a given year getting sufficient treatment through the EAP program that they would require no further treatment. About 15 per cent of the people would then be referred into community programs or into the public health care system.³⁴⁰

EAPs also have a strong prevention component. Much of the work being done with employers focuses on wellness and other programs that support a healthy mental health work environment.

EAPs have been widely adopted across North America and are positively regarded by employers and employees.³⁴¹ They have certain limitations, however. For example, Ash Bender and his colleagues³⁴² expressed concern about the number of therapeutic sessions being offered to EAP clients; based on anecdotal evidence, these have decreased dramatically from seven per individual to fewer than three over the last 10 years. The authors concluded that the likelihood is low of effectively addressing any serious substance abuse or mental illness problem in this limited therapeutic time frame. This concern requires particular attention.

Mary-Ann Baynton, Director, Canadian Mental Health Association in Ontario, suggested to the Committee that it would be helpful if EAPs were able to provide people with access to “advocates” who could assist them in a variety of ways:

That leads to the last recommendation, which is that we should have advocates. Many times, employers will say that they sent out the forms and people never filled them out or called back, they are not doing their part. The employers do not understand that the mental illness itself often makes it impossible for the person to get out of bed, never mind fill out a complicated set of forms. We are looking into having an advocate who can do this on behalf of people with

³⁴⁰ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.5.1, p. 122.

³⁴¹ Neufeldt (2005).

³⁴² Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.5.1, p. 123.

*mental health issues. However, it could be something that the EAPs or the employers themselves could provide.*³⁴³

With regard to EAPs, the Committee recommends:

33 That employers increase the number of counselling sessions offered through Employee Assistance Programs (EAPs), especially in communities where access to other mental health services is limited.

That research be undertaken to evaluate EAPs, and that the results be shared through the Knowledge Exchange Centre that the Committee recommends be created as part of the Canadian Mental Health Commission (see Chapter 16), with a view to strengthening the effectiveness of these programs.

8.4 TRAINING OPPORTUNITIES

Canadians with serious mental illness have relied heavily on community vocational rehabilitation programs that have often struggled to obtain adequate funding. The limited research that has been done suggests that not all vocational rehabilitation approaches achieve the same degree of success in moving people into employment.^{344,345,346}

8.4.1 Vocational Rehabilitation Programs

Vocational rehabilitation programs are intended to help people become or remain economically independent through work. Specialized vocational rehabilitation programs include career counselling, work assessment, work adjustment and conditioning programs, temporary employment and transitional employment placement.

Vocational rehabilitation programs are intended to help people become or remain economically independent through work.

Research into vocational rehabilitation is limited in scope and tends to be descriptive and anecdotal. The assumption behind most vocational rehabilitation is that careful planning combined with a supported and slow re-entry into the workforce will increase the

The evidence available, however, suggests strongly that moving people quickly towards employment is more effective than a gradual, slow re-entry.

³⁴³ 5 July 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁴⁴ Shankar, J., and Collyer, F. (2002) Support needs of people with mental illness in vocational rehabilitation programs — the role of the social network. *International Journal of Psychosocial Rehabilitation*, Vol. 7, 15-28.

³⁴⁵ Lehman, A. F. (1995) Vocational Rehabilitation in Schizophrenia. *Schizophrenia Bulletin*, Vol. 21, No. 4, 645-656.

³⁴⁶ Marrone, J., and Gold, M. (1995) Employment Supports for People with Mental Illness. *Psychiatric Services*, Vol. 46, No. 7, 707-711.

likelihood of success. The evidence available, however, suggests strongly that moving people quickly towards employment is more effective than a gradual, slow re-entry. The longer the delay, the greater the risk in reducing employability through insufficient work experience.³⁴⁷

An additional barrier to employment includes relegating people with mental illness to entry-level, low-wage fields where they often experience little economic progress even when their job retention rates are similar to those of people without disabilities. Minimal expectations by staff, paternalistic protectionism that shields clients from failure, and lack of outcome accountability have all contributed to the low success rate of vocational rehabilitation programs.³⁴⁸

8.4.2 Supported Employment

In the mid-1980s, a new approach to employment emerged, known as supported employment. Its emergence was prompted by a concern to avoid models that tended to foster dependency and to reduce the need for mental health clients to compete in the job market for employment. Supported employment involves placing clients as quickly as possible into jobs without any extensive preparation, while simultaneously providing ongoing, intensive on-the-job support and training using assigned job coaches.

Supported employment involves placing clients as quickly as possible into jobs without any extensive preparation, while simultaneously providing ongoing, intensive on-the-job support and training using assigned job coaches.

Supported employment models have produced more positive outcomes than traditional vocational rehabilitation services.

A comparative research review indicates that supported employment models have produced more positive outcomes than traditional vocational rehabilitation services, brokered vocational rehabilitation services, day treatment programs, pre-vocational programs, or sheltered workshops.³⁴⁹ Reviewing 18 randomized control trials, researchers found that people participating in supported employment programs were significantly more likely to be employed than those who received pre-vocational training (at 12 months, 34% of those in supported employment were employed, compared with only 12% who had pre-vocational training).³⁵⁰ It is important to note however, that this success rate (34%), although positive, remains relatively modest.

8.4.3 Consumer Economic Development Initiatives

Consumer development initiatives emerged in the 1990s as a response by people living with mental illness to the failure of traditional vocational rehabilitation programs to help them achieve their employment goals. People living with mental illness began to develop

³⁴⁷ Marrone, J., and Golowka, E. (1999) If Work Makes People Sick, What do Unemployment, Poverty and Social Isolation Cause? *Psychiatric Rehabilitation Journal*, Vol. 23, No. 2.

³⁴⁸ *Ibid.*

³⁴⁹ Bond, G. R., Drake, R. E., Mueser, K. T., and Becker, D. R. (1997) Supported employment for people with severe mental illness: A review. *Psychiatric Services*, Vol. 48, No. 3, 335-346.

³⁵⁰ Crowther, R., Marshall, M., Bond, G., and Huxley, P. Vocational rehabilitation for people with severe mental illness. *The Cochrane Database of Systematic Reviews* 2001, Issue 2, Art. No.: CD003080. DOI: 10.1002/14651858.CD003080.

businesses which they both owned and operated. The underlying belief was that, if given the tools, they could play an important role both in supporting themselves and in advocating for mental health services and supports that are more effective and accountable.³⁵¹

These initiatives have included self-help organizations in which peer counselors facilitated mutual aid and education initiatives, as well as diverse consumer-run businesses which offered employment opportunities and business development skills to mental health consumers. The research done on consumer-run initiatives demonstrates that this is a promising avenue to move people living with serious mental illness into the workforce.³⁵²

8.4.4 The Club House Model

In many jurisdictions, Club Houses continue to be a mainstay in funded community service delivery. Initially developed in the 1940s by former psychiatric patients, the goal was to help others make the transition from hospital to community.³⁵³ Club Houses offer vocational opportunities, problem-solving groups, case management, recreational activities, and academic preparation.³⁵⁴ They operate under egalitarian rules and are run by staff and clients who seek to provide an accepting, culturally sensitive environment where people can socialize, mutually support each other and gain experience in graded employment opportunities to prepare them for their return to competitive employment.³⁵⁵

The research done on consumer-run initiatives demonstrates that this is a promising avenue to move people living with serious mental illness into the workforce

Pre-vocational training programs are intended to assist people living with mental illness to make the transition to employment through a two-step process. Phase one is the provision of a “work ordered day” where clients work in teams with staff to operate and manage the Club House. The second phase is an opportunity to participate in transitional employment programs where clients are placed in a series of paid but temporary jobs controlled by the Club House. Despite the longevity and continued popularity of this concept, however, there is, however, limited evidence of the efficacy of Club Houses in achieving their vocational goals.

8.4.5 Sheltered Workshops

Widely used up until a decade ago, sheltered workshops now primarily serve the needs of developmentally delayed adults, although some provinces continue to include sheltered workshops in their community-based rehabilitation programs for people with mental illness. The little

Sheltered workshops now primarily serve the needs of developmentally delayed adults.

³⁵¹ Ontario Peer Development Initiative. (October 2003) The History of OPDI. http://www.opdi.org/about_us.html#history.

³⁵² Danley, K. (1996) Proceedings of the Conference on Psychological Disabilities in the Workplace.

³⁵³ The National Mental Health Consumers Self-Help Clearing House.

³⁵⁴ McReynolds, C. (2002) Psychiatric Rehabilitation: The Need for a Specialized Approach. *International Journal of Psychosocial Rehabilitation*, Vol. 7, 61-69. http://www.psychosocial.com/IJPR_7/approach.html.

³⁵⁵ Clubhouse History. <http://www.telusplanet.net/public/club1/history.html>.

research that has been done shows a low success rate (in the range of 5-10%) in assisting people living with a mental illness to obtain non-sheltered employment. In fact, participation in sheltered workshops may further entrench in those involved and the general public alike low expectations of the capacity of people with mental illness to work.

8.4.6 Federal Initiatives

The Opportunities Fund for Persons with Disabilities was originally created as a pilot program in 1997, as part of the Government of Canada's response to the report of the Federal Task Force on Disability Issues (the Scott report) in 1996. Funding for the Opportunities Fund became permanent in December 2000 and is administered by Social Development Canada.

The Opportunities Fund is an employability program for people with disabilities who have had little or no attachment to the labour force. Its objective is to help these people prepare for, get and keep jobs, or to become self-employed.

The Opportunities Fund is an employability program for people with disabilities who have had little or no attachment to the labour force. Its objective is to help these people prepare for, get and keep jobs, or to become self-employed. To meet this objective, the government works in partnership with non-governmental organizations that represent people with disabilities, with the private sector and with provincial governments.

The Opportunities Fund supports initiatives that:

- encourage employers to hire workers with disabilities;
- help people with disabilities build their employment skills, integrate into the labour market and/or become self-employed;
- provide opportunities for work experience that could lead to stable employment; and
- improve access to employment or employment services by providing personal support.

The Opportunities Fund now serves about 4,500 people with disabilities a year, although it is not known what percentage of these are people living with mental illness.

One of the Opportunities Fund's strengths is its individual, flexible approach to delivering services to clients.

According to an evaluation conducted in 2001, one of the Opportunities Fund's strengths is its individual, flexible approach to delivering services to clients. Assessments from Opportunities Fund participants, as well as the outcome data, have also shown that the program has helped individuals find work and has improved their employability and quality of life.

The Committee recommends:

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| 34 | <p>That the Department of Human Resources and Social Development, through the Opportunities Fund for Persons With Disabilities, facilitate the establishment of a nation-wide supported employment program to assist persons living with a mental illness to obtain and retain employment.</p> <p>That this program promote the development of, and provide support for, alternative businesses that are both owned and operated by persons living with mental illness.</p> <p>That the Department of Human Resources and Social Development report on how many people living with mental illness are assisted through the Opportunities Fund for Persons With Disabilities</p> |
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8.5 INSURANCE AND INCOME SUPPORT

8.5.1 Workers' Compensation Boards³⁵⁶

In all provinces and territories, Workers' Compensation Boards (WCBs) receive an increasing number of mental health-related claims (referred to as "occupational stress"); and in a growing number of cases, the Boards have provided compensation for such claims.

A major issue raised with respect to compensation by WCBs concerns the fact that, regardless of jurisdiction, it is more difficult to prove the genesis of a mental disorder than that of a physical illness. As a result, there is some controversy about whether and how mental disorders should be covered under workers' compensation schemes.

A review of occupational stress claims reported to WCBs was undertaken by the Association of Workers' Compensation Boards of Canada to find out how many types of claims were filed on an annual basis, whether they were of an episodic or chronic nature, and how much compensation was paid in each case. This review proved to be very difficult. In many cases, the Boards do not collect this type of data, or if they do, the data are not comparable because the definitions employed by each WCB may be different (see Table 8.1). The review could not, therefore, provide a national perspective on the number of claims resulting from occupational stress and the associated costs of compensation.

Terry Bogyo, Director of Corporate Planning, Workers' Compensation Board of B.C., explained to the Committee that provincial and territorial variations in the treatment of stress disorders was a consequence of the different legislative frameworks that exist in each jurisdiction:

³⁵⁶ This section is drawn largely from: Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, pp. 116-118.

...It is not reluctance on the part of the boards to provide the benefit, because the boards do what the legislation tells us to do. We are the body that gives life to the legislation. ...That variability goes back to the responsibility of legislators to design legislation that is responsive to the social, political, economic, cultural and historical values that are inherent to that jurisdiction. Whether it is right is not for the boards to say. It is our job to administer that legislation. It is not a matter of reluctance. If the legislation says that we cover it, then indeed it would be covered by us.³⁵⁷

A major issue raised with respect to compensation by WCBs concerns the fact that, regardless of jurisdiction, it is more difficult to prove the genesis of a mental disorder than that of a physical illness. As a result, there is some controversy about whether and how mental disorders should be covered under workers' compensation schemes. Under the occupational disease model used by WCBs, compensation for a disability is based on whether the disability arises from continuous exposure to hazardous conditions related to an individual's employment. Yet, as we have seen, most advanced etiological models of mental disorders include a variety of factors, such as genetic vulnerability, developmental circumstances and neurobiological factors, in addition to factors such as a stressful work environment. The relative weight of each of these dimensions is not yet understood, nor is it clear how they fit together.

The Committee believes that it is important for all concerned parties to address these issues and recommends:

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| 35 | That the Canadian Mental Health Commission (see Chapter 16) work closely with provincial and territorial governments as well as with Workers' Compensation Boards, employers and trade unions across the country to develop best practices with respect to compensation for occupational stress-related claims. |
|----|--|

8.5.2 Employer-Sponsored Disability Insurance Plans

Two types of disability income insurance plans are offered by employers: short-term disability (STD) and long-term disability (LTD). STD plans replace a percentage of pre-disability employment earnings (70%, for example) for periods of less than one year's duration (e.g., six months). They are generally harmonized with sick leave, other employee benefits and Employment Insurance (EI) benefits, providing continuity of income for the plan member who has suffered a disabling illness or injury.

Disability income insurance plans are designed to ensure that there is a financial incentive for recipients to return to work.

³⁵⁷ 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

TABLE 8.1
WORKERS' COMPENSATION BOARDS IN CANADA: INTERJURISDICTIONAL
COMPARISON OF OCCUPATIONAL STRESS COMPENSABILITY

| | |
|----------------------------------|---|
| Alberta | <p>Compensation for occupational stress provided if:</p> <ul style="list-style-type: none"> ▪ there is a confirmed diagnosis under the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders; ▪ the work-related events or stressors are the predominant cause of the injury; ▪ the work-related events are excessive or unusual in comparison to the normal pressures experienced by the average worker in a similar occupation; and ▪ there is objective confirmation of the events. |
| British Columbia | <p>Compensable forms of stress include:</p> <ul style="list-style-type: none"> ▪ stress caused by a sudden and unexpected traumatic event; and ▪ stress that results from a compensable injury such as severe anxiety following the amputation of a leg. ▪ Stress that is caused by the pressures encountered in daily personal and work life is not compensable. |
| Manitoba | <p>Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.</p> |
| New Brunswick | <p>Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.</p> |
| Newfoundland and Labrador | <p>Legislative definition of injury covers stress only where it results from an acute reaction to a sudden and unexpected traumatic event and to exclude stress due to labour relations issues.</p> |
| NWT & Nunavut | <p>Claims for occupational stress are considered on a case-by-case basis.</p> |
| Nova Scotia | <p>Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.</p> |
| Ontario | <p>Mental stress is compensable in respect of situations where there is an acute response to a sudden and unexpected traumatic event arising out of and in the course of employment.</p> <p>Mental stress due to the employer's employment decisions does not entitle a worker to benefits.</p> |
| Prince Edward Island | <p>Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.</p> |
| Quebec | <p>Stress is compensable if the worker can show a relationship between the illness and the work or a risk in the work.</p> |
| Saskatchewan | <p>Compensation for occupational stress is specifically allowed for as a matter of policy where clear and convincing evidence is provided that the work stress was excessive and unusual; routine industrial relations actions taken by the employer are considered normal and not unusual.</p> |
| Yukon | <p>Post-traumatic stress considered compensable under legislation; current practice is to assess all other stress-related claims on a case-by-case basis.</p> |

Source: Kishchuk, P. (March 2003) *Expansion of the Meaning of Disability*. Paper commissioned by the Yukon Workers' Compensation Board, p. 12.

LTD plans focus on longer periods of disability. They typically commence payments after the disabled individual has been off work for a significant period, such as six months, and replace a specified percentage of the person's pre-disability employment income, for example 70%. LTD benefits typically run for up to two years for recipients who are unable to perform their own jobs, and can continue to a limit of age 65 or the onset of retirement benefits for recipients who cannot perform their own or any reasonably comparable job. LTD benefits provided by the employer's plan may be reduced by the amount obtained by the recipient under the Canada Pension Plan (Disability) (CPP(D) — see below).

Employers, managers and insurers must become more knowledgeable about mental illness and addiction in order to better manage disability claims.

An important aspect of both STD and LTD plans is the commitment to assist recipients to return to the workplace, preferably to their own jobs, or to another job if that proves not to be feasible. Consistent with this commitment, disability income insurance plans are designed to ensure that there is a financial incentive for recipients to return to work; thus disability income replacement benefits do not exceed, and are usually less than, pre-disability employment income. Disability insurance should not be a disincentive to work. In this context, the Canadian Psychiatric Association explained:

Disability insurance for any illness requires a precise definition of that illness. Whereas it is important that disabled psychiatric patients receive an adequate income to protect themselves from serious financial reverses over the time that they are not able to work, it is just as important to recognize that disability payments may constitute a major secondary gain actually impeding a patient's progress and delaying rehabilitation. There are two factors to be considered: a) the prevalent misconception that work is ipso facto stressful and likely to aggravate a diagnosed psychiatric disorder; and b) the recognition that some patients who have undergone a serious psychiatric disorder may want to avoid exposure to what they presume to be stressful factors at work because of lack of confidence even after they have improved clinically. It should be recognized that return to work as soon as possible is likely to improve the patient's self-esteem, reestablish him/her in a familiar social network and otherwise aid rehabilitation. There is some evidence that work deprivation may be one of the causes of psychiatric disorder.³⁵⁸

Employers, managers and insurers must become more knowledgeable about mental illness and addiction in order to better manage disability claims. During a recent speech, Bill Wilkerson, co-founder and CEO, Global Business and Economic Roundtable on Addiction and Mental Health, commented:

³⁵⁸ Canadian Psychiatric Association. (1988) Insurability of the Psychiatrically Ill or Those With a Past History of Psychiatric Disorder. Position Paper.

[The insurance] industry must develop a perspective based on knowledge of mental health issues. Like business generally, the insurance sector needs a mental health education agenda.

An example of where this is especially true is in the comorbidity of mental illness and physical chronic diseases as this pertains to: origin and the duration of human disability; the complexity, lengths and risks of treatment and recovery; and, the pace and timing of the sufferer's return to work.

The insurance industry needs — at the levels of claims management — to know more about the medical science of mental health. ... The industry needs to develop a knowledge base about the expanding universe of neuroscience and its illumination of the origins of behaviour.

8.5.3 Provincial and Territorial Social Assistance Programs

Insurance and income support programs provide some level of protection for persons living with mental illness who find themselves unable to work. However, programs operated by workers' compensation boards, employers, and the Government of Canada (e.g., CPP(D) and EI) share a key attribute — to qualify, individuals must have a job, often for a prolonged period of time. This, coupled with a myriad of other eligibility criteria and time-limited benefits, frequently results in people living with mental illness having to turn to the income assistance programs of last resort — social assistance (i.e., welfare) programs operated by the provinces and territories.

Strict eligibility criteria, including a requirement to first exhaust one's own financial assets, are not the only problem associated with social assistance programs for persons with disabilities. Benefits, while generally higher than those available under general welfare assistance programs, remain at a level that may result in financial hardship.

Most often, social assistance programs distinguish between individuals who are able to work but unable to find employment, and those who are unable to work due to illness, disability or other cause. For example, the Government of Ontario operates the Ontario Works program to assist those persons who are able to work but unable to find employment. Here, applicants are expected to first use up their personal assets before they become eligible for assistance. Benefit levels are low, and recipients are required to participate in retraining or other "employment activities." In short, "eligibility rules are designed to ensure that people turn to welfare only when all other financial resources have been exhausted."³⁵⁹

In contrast, those who are unable to work may be streamed into the Ontario Disability Support Program (ODSP). Benefit levels are roughly twice those of Ontario Works, and while recipients are encouraged to work to the greatest extent possible, participation in

³⁵⁹ Government of Ontario, Ministry of Community and Social Services. Who is Eligible for Ontario Works? <http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioWorks/FAQs/OW-q-eligibility.htm>.

related programs, such as retraining, is voluntary. Also, applicants may retain a small amount of personal assets, some \$5,000 in cash and RRSPs.³⁶⁰

Unfortunately, as is the case with other income support programs, eligibility for ODSP is restricted. Applicants must “have a substantial physical or mental impairment that is continuous or recurrent and is expected to last one year or more.” Given the cyclical and unpredictable nature of mental illness, persons living with mental illness, and unable to work, may find themselves ineligible for ODSP. They are thus forced instead to rely on Ontario Works, even though they are not the target group for this program.

Those who seek to return to work may be dissuaded by policies that would result in varying amounts of earned income being deducted from their benefit cheques, a loss of specific benefits (i.e., medical or drug benefits) or a loss of benefits altogether.

Strict eligibility criteria, including a requirement to first exhaust one’s own financial assets, are not the only problem associated with social assistance programs for persons with disabilities. Benefits, while generally higher than those available under general welfare assistance programs, remain at a level that may result in financial hardship. The following table includes a sampling of assistance rates and earning exemption amounts (i.e., the amount that can be earned before benefits are reduced) from across Canada:

| | British Columbia | Ontario | Quebec |
|--|-------------------------|-------------------------|-------------------------|
| Amount per month for a single person with a disability | \$856.42 ³⁶¹ | \$959.00 ³⁶² | \$835.67 ³⁶³ |
| Earning Exemption Amount | \$400.00 ³⁶⁴ | \$160.00 ³⁶⁵ | \$100.00 ³⁶⁶ |

³⁶⁰ Government of Ontario, Ministry of Community and Social Services. ODSP Handbook. http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm.

³⁶¹ Government of British Columbia, Ministry of Employment and Income Assistance. BC Employment and Assistance Rate Tables — Disability Assistance — Effective 1 January 2005. <http://www.eia.gov.bc.ca/mhr/da.htm>.

³⁶² Government of Ontario, Ministry of Community and Social Services. ODSP Handbook. http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm.

³⁶³ Government of Quebec, Emploi et Solidarité sociale. Basic Benefit. http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base_en.asp.

³⁶⁴ Government of British Columbia, Ministry of Employment and Income Assistance. Fact Sheet — Earnings Exemption for Persons With Disabilities. http://www.eia.gov.bc.ca/factsheets/2004/PWD_EarningsExemption.htm.

³⁶⁵ Government of Ontario, Ministry of Community and Social Services. ODSP Handbook. http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm.

³⁶⁶ Government of Quebec, Emploi et Solidarité sociale. Basic Benefit. http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base_en.asp.

Those who seek to return to work may be dissuaded by policies that would result in varying amounts of earned income being deducted from their benefit cheques, a loss of specific benefits (i.e., medical or drug benefits) or a loss of benefits altogether.

Joan Edwards-Karmazyn, Manager, Consumers Health Awareness Network Newfoundland and Labrador (CHANNAL), summed up the dilemma faced by persons living with mental illness who rely on social assistance programs, saying:

The members of CHANNAL expressed a need for more affordable housing; fewer barriers to receiving educational and vocational services; and increased wage earning allowances while receiving social income supports.

Members state that they are caught in the system due to the need...for medication allowances. Therefore, one is hesitant to stop income allowances as stopping income allowances has a direct impact on also having medication benefits stopped. People are afraid to come off their benefits because the income they would make out in the real work world would not allow them to afford the \$1,500 a month for medication alone.³⁶⁷

Therefore, the Committee recommends:

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| 36 | That benefit levels and earning exemption amounts for social assistance programs for persons living with a mental illness be increased to reduce financial hardship and increase the incentive to work. That recipients of supplementary aid, such as help with the costs of medication, continue to be eligible for assistance for an extended period of time even if their incomes increase to levels where they are no longer eligible for financial aid for shelter or other living expenses. |
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8.5.4 Federal Income Security Programs³⁶⁸

The federal government has two income support programs that may be of assistance to persons living with a mental illness: the Disability Benefit provided by the Canada Pension Plan, and sickness benefits provided by Employment Insurance. Tax assistance is available through the Disability Tax Credit.

³⁶⁷ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁶⁸ This section is drawn largely from: Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, pp. 118-120.

8.5.4.1 Canada Pension Plan (Disability) Program (CPP(D))

The Canada Pension Plan (Disability) program is the largest single disability income program in Canada. It is generally the “first payer” of disability benefits, preceding other entities such as provincial workers’ compensation boards and private insurance companies.

CPP(D) benefits are paid to contributors under age 65 who have a physical or mental disability that is “severe and prolonged” (lasting at least one year and preventing work on a regular basis) and who meet specific requirements relating to the level of earnings and years of contribution (contributions must have been paid in four out of the previous six years). Between 1980 and 2000, the proportion of individuals receiving CPP(D) benefits attributable to mental disorders increased sharply — from 11% to 23%. Mental illness ranked second, behind disease of the musculoskeletal system, and affected a higher proportion of females than males. In 2000, mental disorders also represented the most prominent cause of CPP(D) disability among younger beneficiaries.

For many years, individuals with mental illness and addiction and their representatives have raised concerns that CPP(D) does not address the question of mental illness and disability appropriately. For example:

- Many individuals with mental illness have limited work histories. Because mental illness often strikes in early adulthood at a time when education, job skills and careers are being developed, many of these individuals are not eligible for CPP(D) due to their having insufficient years of employment. Out of necessity, many turn to provincial social assistance programs for support.
- To qualify for CPP(D) disability benefits, the beneficiary must accept the designation of having a “severe and prolonged” disability that means they cannot pursue any gainful employment on a regular basis. Because of the cyclical and unpredictable nature of mental disorders, many individuals with mental illness can work, but often only on a part-time basis; they are not necessarily capable of achieving full financial independence. In this vein, Jason Turcotte, of the Canadian Mental Health Association Office in Portage La Prairie, a member of the Partnership for Consumer Empowerment, told the Committee that “the all-or-nothing approach must be eliminated. To provide benefits only to someone while they are 100-per-cent disabled is discriminating, disempowering, and a disincentive to recovery.”³⁶⁹ Individuals with mental illness and addiction have recommended

To provide benefits only to someone while they are 100-per-cent disabled is discriminating, disempowering, and a disincentive to recovery.

— **Jason Turcotte**

Since disability is currently equated with permanent unemployment, individuals on CPP(D) are reluctant to look for or take employment for fear of losing their benefits.

³⁶⁹ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

that CPP(D) pay partial or reduced benefits rather than full benefits to enable them to work part-time and still retain a portion of their benefits.

- Since disability is currently equated with permanent unemployability, individuals on CPP(D) are reluctant to look for or take employment for fear of losing their benefits. Those affected are penalized for trying to improve their circumstances even if they are not capable of participating in regular full-time work again.
- Just over half of all initial applications to CPP(D) are denied; almost two-thirds of those rejected do not apply for reconsideration. It has been suggested that the proportion of applications rejected from those with mental illness is much higher. Some claim that the system is designed in such a way as to discourage individuals from pursuing rightful claims. This is particularly true for individuals with mental disorders who, because of their illness, may lack the ability to “push the system.”

Just over half of all initial applications to CPP(D) are denied.

Once qualified for CPP(D), individuals are often reluctant to make any attempt to return to work or engage in other activities that could bring their declared impaired health status into question.

Once qualified for CPP(D), individuals are often reluctant to make any attempt to return to work or engage in other activities that could bring their declared impaired health status into question. Many fear that to do so risks triggering a reassessment of their CPP(D) eligibility, and raises the potential of a loss of income support. According to one individual living with mental illness:

CPP-Disability puts individuals in a position of having to paint themselves in the worst possible light, and define themselves in the most negative way, just to convince the worker they actually require assistance. The entire process is based on pathology rather than recovery.³⁷⁰

An additional concern is that CPP(D) may also inadvertently contribute to the process by which persons living with mental illness come to be viewed as permanently unemployable. Private insurance companies, in an effort to reduce their financial liability, often require their clients to apply for CPP(D) because of its “first payer” status. However, moving from employer-sponsored private insurance coverage to CPP(D) may further distance the individual from his or her employer, making a return to work more difficult.

Some progress has been made in addressing a number of these issues in recent years. For example, an allowable earnings provision gives recipients the flexibility of earning up to \$4,100 a year while remaining on CPP(D) benefits. Greater personalized contact with applicants means that clients receive telephone calls during the decision-making process to

³⁷⁰ Canadian Mental Health Association. (27 November 2001) Position Paper on Federal Income Security Programs, submitted to the House of Commons Subcommittee on the Status of Persons With Disabilities. <http://www.disabilitytax.ca/subs/cmha-e.pdf>.

discuss individualized needs and provide appropriate information about programs and services.

As well, a legislative change to the CPP was made in 2005 allowing for the automatic reinstatement of CPP(D) benefits. This provision allows beneficiaries who are able to return to employment to try working without fear of losing their CPP(D) benefits. If their disability recurs within a two year period, these clients are quickly returned to benefits. Cecilia Muir, Director General, Office of Disability Issues, Social Development Canada, explained to the Committee the significance of this modifications to CPP(D):

I acknowledge it is not a whole solution, but this is a huge step forward. This feature allows a person for up to five years not to have to go back through a reapplication and all the process that one would normally need to go through. ... The projections were that at least 300 persons a year would be able to benefit. Those are individual people.³⁷¹

Finally, to make people more aware that CPP(D) supports clients in their efforts to return to work without risking a loss of benefits, the program has implemented a communication strategy. Communication tools include an annual “Staying in Touch” newsletter, website and annual correspondence to clients outlining CPP(D) return to work provisions. In addition, clients who are most likely to benefit from automatic reinstatement, in particular those with episodic disabilities, receive letters explaining how the new provision works.

In its 2003 report, the House of Commons Standing Committee on Human Resources Development and the Status of Persons with Disabilities recognized that CPP(D) does not address the question of mental illness and disability appropriately. The Committee made a number of recommendations to ensure that CPP(D) takes into account the cyclical and unpredictable nature of mental illnesses. In addition, it recommended that the federal government develop, in consultation with stakeholders and health care professionals, specific evaluation tools for these particular disabilities to be used in assessing eligibility for CPP(D).

In its response to the House of Commons committee’s report, the federal government indicated that CPP(D) guidelines already recognize recurrent and episodic disabilities, including mental disorders, and that many individuals with mental disorders currently receive CPP(D) benefits. Furthermore, it stated:

The Government therefore does not believe regulations and guidelines need to be changed to accommodate the needs of individuals with episodic or recurring conditions. Because the determination of disability for CPP is based on the functional limitations that prevent a person from working, and not simply on a medical diagnosis or prognosis, the adjudication process is able to take into consideration the short- and long-term impacts of recurrent

³⁷¹ http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

or episodic medical conditions on the client's ability to function in the workplace.³⁷²

The Committee strongly rejects this view, and it recommends:

37 **That the eligibility criteria for Canada Pension Plan — Disability (CPP-D) benefits be modified so that persons living with a mental illness are no longer required to demonstrate that their illnesses are severe and prolonged, but only that their illness has been diagnosed and that they are unemployable and need income support.**

That the Government of Canada review how to coordinate better Employment Insurance (EI) sickness benefits and CPP-D, and examine how to eliminate structural barriers (i.e., financial disincentives) that limit opportunities to return to work.

That the Government of Canada grant authority to the CPP to permit it to sponsor research on, and the testing of, new approaches that could target people with episodic disabilities, particularly episodic mental illness.

That the Government of Canada explore ways to provide incentives to employers who hire persons living with mental illness, including the possibility of offering them CPP premium “holidays”.

8.5.4.2 Employment Insurance (EI)

Individuals with mental illness may also be eligible to receive EI benefits as a source of temporary income replacement. Some concerns have been raised, however, with respect to EI:

- In terms of EI eligibility, employees who are dismissed because of “misconduct” or quit “without just cause” are not eligible for EI benefits. Due to stigma, individuals with mental illness in the workplace often conceal their illness. When they experience difficulty on the job, they may be fired or may quit as a result of their illness, but would not be in a position to claim EI benefits because they have not previously disclosed their illness.
- When a person applies for EI sickness benefits, he/she is required to obtain a medical certificate indicating how long the illness is expected to last. The unpredictable nature of mental illness makes it difficult to provide this kind of medical information.

³⁷² Human Resources Development Canada. (November 2003) Government of Canada's Response to “Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program,” p. 22.

- Individuals with mental illness and addiction share the view that EI should exempt individuals with recurring illnesses or disabilities from fulfilling the additional number of insurable hours required of those who are considered new to the labour force. In their view, without this exemption, individuals with mental illness are unjustly disadvantaged. Few are able to meet the eligibility criteria in terms of the total number of insurable hours required of new workers.

In his brief to the Committee, Dr. Sunil V. Patel, then President of the Canadian Medical Association, recommended that the federal government review CPP(D) and other federal income support policies to ensure that mental illness is on a par with other chronic diseases and disabilities in terms of the benefits available to affected persons.

The Committee is of the view that the criteria for EI sickness benefits should be modified so that persons living with a mental illness can qualify more easily for EI. Given the enormity of the surplus in the EI Account,³⁷³ this change would not represent an undue burden on the public purse.

Therefore, the Committee recommends:

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| 38 | That Employment Insurance (EI) sickness benefits be modified so that persons living with a mental illness can qualify more easily. Specifically, for persons living with a mental illness, the number of hours to be worked since the last claim should be reduced. |
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8.5.4.3 Disability Tax Credit (DTC)

The Disability Tax Credit³⁷⁴ is a non-refundable tax credit that can be used by persons with disabilities to reduce the amount of income tax they have to pay. A person can transfer the credit to his or her spouse, or to another supporting person. It is intended to help persons with disabilities bear the additional costs of living and working generated by their disability. The basic credit is worth \$1,037.76 per year.

Qualifying for the DTC is not an easy task. In order to be successful, a person must have a severe and prolonged (i.e., minimum of one year) impairment that markedly restricts his or her ability to perform a basic activity of daily living. The definition of “basic activity of daily living” is highly restrictive, and does not include working, housekeeping, recreational or

³⁷³ In her November 2004 Report, the Auditor General indicated that the accumulated surplus in the EI Account had risen to \$46 billion. See: Office of the Auditor General of Canada, November 2004 Report, Chapter 8. <http://www.oag-bvg.gc.ca/domino/reports.nsf/html/20041108ce.html#ch8hd3b>.

³⁷⁴ For a more detailed explanation of the Disability Tax Credit, see: Canada Revenue Agency, Disability amount. <http://www.cra-arc.gc.ca/agency/resourcekit/individuals/benefits-dtc-e.html>.

social activities.³⁷⁵ Also, the amount of tax relief is small. Therefore, the Committee recommends:

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| 39 | That the eligibility criteria for the Disability Tax Credit (DTC) be modified so that persons living with a mental illness can qualify more easily, and that the amount of the DTC be increased. |
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³⁷⁵ “Basic activity of daily living” means one of the following: perceiving, thinking, and remembering, feeding, dressing, speaking so as to be understood by a person familiar to you in a quiet setting, hearing so as to understand a person familiar to you in a quiet setting, eliminating (bowel or bladder functions), walking.

9.1 INTRODUCTION

One of the biggest challenges for addictions in the health system is that ministers have to choose between MRIs and junkies, to be blunt. There is no political traction...—Michel Perron³⁷⁶

In Canada, the treatment of addiction, like that of mental health, is not a “system.” Its evolution has been fragmented, chronically underfunded, and has occurred in the shadow of stigma and government inattention. Yet, there are few Canadian families who have not been touched by addiction.³⁷⁷ Over the course of its hearings, the Committee heard much about the devastation caused by addiction: family breakdown, financial losses, child prostitution, crime, homelessness, domestic violence and child abuse, concurrent health problems, road and industrial accidents, job loss, birth defects, brain damage and suicide. The connection between addiction and these consequences often goes unrecognized because of stigma and denial. When people with addictions come to the point where they need and will accept help, they and their families have a hard time finding services; even when successful, they often face long waiting lists. Lengthy wait times mean those who might otherwise be helped, withdraw further into addiction with a resulting increase in the human and social consequences.

When people with addictions come to the point where they need and will accept help, they and their families have a hard time finding services; even when successful, they often face long waiting lists.

30% of people diagnosed with a mental illness will also have a substance abuse problem in their lifetime, and 37% of people who abuse alcohol (53% who abuse drugs) also have a mental illness.

Mental health and addiction services operate in separate spheres. The idea that some people with a substance abuse problem might also have a mental illness and that those living with mental illness might also be addicted has taken time to emerge. However, research has revealed that 30% of people diagnosed with a mental illness will also have a substance abuse problem in their lifetime, and 37% of people who abuse alcohol (53% who abuse drugs) also have a mental illness.³⁷⁸

When mental illness and an addiction are present together, there is the added burden of being shunted back and forth.

³⁷⁶ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁷⁷ Throughout this chapter, the term “addiction” is used for simplicity’s sake. It is recognized that harm due to substance use and abuse can occur without addiction being present: through binge drinking, intoxication and unsafe drug use that result in health problems, road accidents, falls and other adverse consequences. Substance use exists on a continuum with limited, safe use at one end and addiction at the other — but the potential for harm may occur at many points along this continuum.

³⁷⁸ Skinner, W., O’Grady, C., Bartha, C., and Parker, C. (2004) Concurrent substance use and mental health disorders: An information guide. Toronto: Centre for Addiction and Mental Health.

Consumers and families are frustrated trying to get help from mental health services or from addiction services. But when mental illness and an addiction are present together, there is the added burden of being shunted back and forth as professionals argue over which problem constitutes the “primary” diagnosis.

I've gotten help for each individual thing but to get help for (both), like at the same time, you fall between the cracks and if one of your disorders is worse than another and then one doctor thinks you're seeing somebody else, basically nobody's helping you, nobody follows up, you kind of disappear.
—Anonymous³⁷⁹

The Committee acknowledges that it has not been able to devote as much attention to substance use issues as it intended when it embarked on its study of “mental health, mental illness and addiction.” The Committee recognizes that this report concentrates primarily on mental health issues and is acutely aware that it only scratches the surface of many substance use issues that deserve a much fuller treatment.

There are, of course, many areas of overlap between mental health and substance use issues, not least of which involve people living with both mental health and substance use disorders. Because of the importance of substance use issues in general, and of this overlap in particular, this chapter of the report is devoted to these issues. Moreover, there is an important recommendation in Chapter 16 (National Mental Health Initiatives) that the federal government inject an additional \$50 million per year in concurrent disorder programs.

9.2 THE HUMAN FACE

A strong consumer and family self-help and advocacy movement has arisen in support of mental health services. With regard to addiction, too, self-help has had a pervasive presence with a long history — but within a culture of anonymity and independence, and with little government funding. This may explain why so few people with addictions, or their family members, testified before the Committee or submitted briefs.

With regard to addiction, self-help has had a pervasive presence with a long history — but within a culture of anonymity and independence, and with little government funding. This may explain why so few people with addictions, or their family members, testified before the Committee or submitted briefs.

Clean and Sober Thinking (CAST) is an unfunded addiction consumer organization based in Peel Region Ontario. CAST meetings provide support at a crucial time for an addict on the cusp of change. When someone in the soul destroying world of addictions decides to reach out, the fear is all-encompassing. The window of time in which a response is needed is brief and urgent. There is no comfort like that which is given by those who have been there — or in the case of a CAST meeting — those who are there. In Ontario, there is a whole

³⁷⁹ Rush, B. (undated) Concurrent mental and substance use disorders: Why is such “double trouble” so important? Submission to the Standing Senate Committee on Social Affairs, Science and Technology, p. 7.

culture of funded consumer initiatives for the mental health sector. There are no funded consumer initiatives for people with addictions. —Tom Reghr³⁸⁰

The testimony available to the Committee gave only a small glimpse into the pain caused by addiction.

I speak personally because my daughter, who has schizophrenia, is on crack. [...] How can we expect a person with a serious mental illness whose cognitive abilities are affected, who has little or no motivation or insight, who lives a sort of hand-to-mouth existence every day, how can they ever manage to quit? The interventions, and resources and treatment facilities are hopelessly inadequate. The general attitude is to wait until they are ready to quit. Well, they do not want to quit. —Joan Nazij³⁸¹

More people than we know are addicted to gambling — writing bad checks, lying, stealing, skipping work — all to feel the high of the instant gratification. But unlike other addictions, it is often hidden. There is no wavering gait, no slurred speech, no needle tracks. For three years, none of my friends knew I gambled. I went alone, and usually late at night. Playing the slots...at any cost, was my number one obsession. —Anonymous

The pain pill addiction stripped me of my dignity and cost me a great deal. Aside from taking money from my family, I borrowed and stole the trust and faith they had in me. Nothing became as important as the high. I had to take more pills just to try and recapture the elusive feeling. The pills only exacerbated the struggles I was facing. I could finally see what had been only too clear to many others — my life was a mess. I was financially broke and my spirit was on overdraft. —Barry Strader³⁸²

The addiction field lacks powerful voices, a vacuum that has left only policy makers and health providers to speak for anonymous clients. However good their advocacy, there is no substitute for direct testimony from people who are, or have been, “there.” Individuals and families living with mental illness have successfully made the case to various provincial and territorial governments that the contributions of self-help organizations are so important that they must be funded. That this has not been done for addictions sets up inequality of representation between two groups, *both* of whom have crucial expertise to offer and important work to do.

The addiction field lacks powerful voices.

³⁸⁰ Reghr, T. (September 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 2.

³⁸¹ 6 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁸² Strader, B. (undated) Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

Therefore, the Committee recommends:

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| 40 | That a portion of the funding for peer support in the Mental Health Transition Fund (see Chapter 16) be made available to develop and sustain self-help and peer support groups for people and their families living with addiction (including problem gambling). |
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9.3 FAMILIAR CULPRITS AND THE DAMAGE THEY CAUSE

While the production and trafficking of illicit drugs grabs headlines, legally available substances — alcohol³⁸³ and prescription medication — have the greatest and most far-reaching impact on Canadians' lives and health, principally because of their pervasive presence and common usage.³⁸⁴

Legally available substances — alcohol and prescription medication — have the greatest and most far-reaching impact on Canadians' lives and health, principally because of their pervasive presence and common usage.

When you look at the idea of somebody who is addicted, you tend not to look at alcohol. If you do, it is a person sitting in an alleyway with a brown paper bag. You do not look at it as being the drinker inside the home; you do not look at prescription drugs and those kinds of things. The sensationalized reporting [on illicit drugs] does not help because what is in the news are the sensational stories, not the day-to-day lives of people. —Senator Cordy³⁸⁵

Prenatal exposure to alcohol is now considered to be the *leading* cause of birth defects in North America. The magnitude of the problem of abuse of legal substances in Canada is often ignored because of stigma and denial. Nonetheless, the facts are clear:

Prenatal exposure to alcohol is now considered to be the leading cause of birth defects in North America.

- 13.6% of all Canadians are considered high-risk drinkers.³⁸⁶
- In any given year, it is estimated that 8% of all hospitalizations and 10% of the total number of days in hospital are attributable to substance abuse.³⁸⁷

³⁸³ Tobacco is also a significant factor in negative health consequences.

³⁸⁴ Tim Stockwell, Michel Perron, Greg Purvis, and Jeff Wilbee, 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁸⁵ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

³⁸⁶ Canadian Centre on Substance Abuse. (March 2005) Canadian Addiction Survey (CAS): A national survey of Canadians' use of alcohol and other drugs: Prevalence of use and related harms. Available at: www.ccsa.ca.

³⁸⁷ Single, E., Robson, L., Xiaodi, X., and Rehm, J. (1996) The costs of substance abuse in Canada. Available at: www.ccsa.ca.

- Prenatal exposure to alcohol is now considered to be the *leading* cause of birth defects in North America.³⁸⁸
- In 2000, a total of 981 people died in alcohol-related vehicle crashes in Canada (including pedestrians and off-road vehicles).³⁸⁹
- Canadians are among the highest per capita users of psychiatric medications in the world. Canadians are the second-highest users of sedatives and the fourth-highest of prescription narcotics.³⁹⁰
- It is estimated that 20% of Canadians over 60 are long-term users of pain-killers.
- Women are 50% more likely to abuse medication than men. Aboriginal populations are particularly at risk for non-medical use of prescription medication.³⁹¹
- Abuse of legal substances (including tobacco) accounts for \$11.8 billion in annual productivity losses in Canada, or 1.7% of the gross national product (GNP), a cost that works out to \$414 for every man, woman and child in Canada.³⁹²

Canadians are among the highest per capita users of psychiatric medications in the world. Canadians are the second-highest users of sedatives and the fourth-highest of prescription narcotics.

Abuse of legal substances (including tobacco) accounts for \$11.8 billion in annual productivity losses in Canada.

The reality is that the vast majority of Canadians who are addicted use legally available substances.

Ballpark, it would be 90 per cent of deaths caused by drugs are from alcohol and tobacco. If you look at disability and quality of life, it would probably be more like 95 per cent. The analysis done by the World Health Organization globally, including looking at economically developed countries such as Canada, shows this very clearly. —Tim Stockwell³⁹³

The reality is that the vast majority of Canadians who are addicted use legally available substances. Many people are cross-addicted, meaning that they use alcohol and medication in a variety of combinations. Addiction is a health problem in which incidence can be affected by monitoring interventions (in relation to prescription drug use, for example,) and public awareness of the dangers.

³⁸⁸ Health Canada, First Nations and Inuit Health Branch. (2004) Literature review: Evaluation strategies in Aboriginal substance abuse programs: A discussion. (2004) Available at: www.ccsa.ca.

³⁸⁹ Canada Safety Council. (2005) Alcohol-Crash Stats. Available at: www.safety-council.org/info/traffic/impaired/stats.html.

³⁹⁰ Rehm, J., and Weeks, J. (2005) Abuse of controlled prescription drugs. In Substance abuse in Canada: Current challenges and choices. Ottawa: Canadian Centre on Substance Abuse. Available at: www.ccsa.ca.

³⁹¹ *Ibid.*

³⁹² Canadian Centre on Substance Abuse, and Centre for Addiction and Mental Health. (1999) Canadian Profile 1999. Available at: www.ccsa.ca.

³⁹³ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Therefore, the Committee recommends:

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- 41 **That treatment resources targeted at addictions include addiction to legal substances such as alcohol, tobacco, and prescription medications, and to behaviors such as gambling.**

9.4 A NEW THREAT — PROBLEM GAMBLING

The prevalence of problem gambling has risen significantly over the past 25 years. In Ontario it is estimated that 3.8% of citizens (340,000 people) have moderate to difficult problems related to gambling; an additional 0.9% are severely addicted.³⁹⁴ In 1999-2000, the net profit from gambling (after prizes and other expenses) to governments at all levels was \$5.7 billion.³⁹⁵ By 2004, that profit had risen to \$6.2 billion, more than the net profit to government of tobacco and alcohol combined (\$5.9 billion).³⁹⁶

Experts fear that most of the problems related to gambling remain hidden because of shame and stigma.

High school students gamble at two to four times the rate of the general public.

British Columbia, Manitoba, Quebec, Alberta, Ontario and Prince Edward Island have “responsible gaming” programs related to problem gambling. Ontario’s commitment is 2% of gross revenues from slot machines in charitable casinos and at racetracks, the largest allocation to a problem gambling strategy anywhere in the world. In a recent review, however, it was found that the fund has not been fully disbursed (only \$21.7 of the \$36 million allocated was released in 2003-2004). Fewer (5,900) than the expected number of problem gamblers (8,600) sought treatment.³⁹⁷

Experts fear that most of the problems related to gambling remain hidden because of shame and stigma, but that they will emerge in due course and in overwhelming numbers. One indicator of what is to come is that high school students gamble at two to four times the rate of the general public — the problem gamblers of tomorrow.³⁹⁸

Canadian governments at all levels depend on revenues from gambling; it is likely that investment in gambling facilities will be increased. But the social, economic and health impacts for Canadians are just beginning to emerge and must not be ignored or minimized.

³⁹⁴ Simpson, R. Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology.

³⁹⁵ Canada West Foundation. (2001) *Gambling in Canada 2001: An Overview*. Available at: www.cwf.ca.

³⁹⁶ Skinner, W. (September 2005) Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

³⁹⁷ Sadinsky, S. (March 2005). Review of problem gambling and responsible gaming strategies of the Government of Ontario: A report to the Ontario Ministry of Health and Long-term Care and the Ministry of Economic and Trade Development. Available at: www.health.gov.on.ca/.

³⁹⁸ Youth Gambling International. (2004) *Youth problem gambling*. Available at: www.education.mcgill.ca.

Therefore, the Committee recommends:

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| 42 | <p>That provincial and territorial governments commit a fixed portion of funds derived from gambling to evidence-based prevention, awareness and treatment programs for gambling addiction, and to gambling addiction research.</p> <p>That Statistics Canada ensure that in addition to alcohol and drug use, the prevalence of problem gambling among the general population is measured and reported upon through regular survey work.</p> |
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9.5 THE MOST VULNERABLE

As with other health problems, people who are poor, marginalized or otherwise disadvantaged suffer disproportionately from addictions and/or problem gambling. Children and youth, women and seniors have particular vulnerabilities that may not be recognized and, as a result, are not addressed.

People who are poor, marginalized or otherwise disadvantaged suffer disproportionately from addictions and/or problem gambling. Children and youth, women and seniors have particular vulnerabilities.

9.5.1 First Nations, Inuit and Métis Peoples

As described in Chapter 14, Aboriginal people attribute their mental health and addiction problems to a history of colonization that assaulted their culture and created a pervasive atmosphere of despair.³⁹⁹ Constant relocation of communities and the removal of children from families to residential schools disrupted traditional connections to family and community; whole generations were dislocated and traumatized. The effects are a weakened cultural identity, poverty, dependence on social welfare, and a profound sense of grief.⁴⁰⁰

First Nations, Inuit and Métis peoples suffer a host of health problems, not the least of which is addiction.

In Labrador alone, as the man was saying from the reserve, there have been an awful lot of suicides of young people. This is not limited to Labrador, but happens in St. John's and all over the province from depression. There are also

³⁹⁹ Brant, C. (1993) Suicide in Canadian Aboriginal peoples: causes and prevention. In the Royal Commission on Aboriginal Peoples: The path to healing: Report on the national round table on Aboriginal health and social issues. Ottawa: Department of Supply and Services.

⁴⁰⁰ Mussell, B., Cardiff, K., and White, J. (2004) The mental health and well being of Aboriginal children and youth: Guidance for new approaches and services. Available at: www.mheccu.ubc.ca.

a lot of suicides in this province from those video lottery terminals and...from overdoses with drugs.... —Harold Dunne⁴⁰¹

9.5.2 Women

Women differ from men in many respects, including their responses to substance use. For example, women are more likely than men to develop cirrhosis of the liver with less consumption of alcohol over shorter periods of time.⁴⁰² They are also more likely to be victims of domestic assault, child abuse and sexual violence; women who have suffered such experiences are more likely to develop substance abuse problems.⁴⁰³ Because of the risk of birth defects, women of child-bearing years who are drinking or using drugs are of particular concern.

Because of the risk of birth defects, women of child-bearing years who are drinking or using drugs are of particular concern.

The system would benefit from more outreach services (educational seminars in places where high risk women gather naturally). These services not only help identify pregnant and parenting women but they are encouraged to begin treatment. Outreach is also critically needed for other populations like elderly women, youth, the chronic or severely addicted woman who is often homeless, and women offenders. These women frequently do not or cannot access services and we need to reach out to them with understanding and sensitivity. — Nancy Bradley⁴⁰⁴

9.5.3 Seniors

Up to 18% of hospitalized seniors are there because of alcohol abuse. Older adults use more prescription medication and, as a result, are particularly vulnerable to adverse drug reactions and interactions, and drug dependence.

Up to 18% of hospitalized seniors are there because of alcohol abuse.

In addition, problem gambling may be on the increase among seniors. An Ontario study found that 6.4% of seniors who gambled were at risk of addiction, with 0.1% already gambling at problem levels. A Manitoba study found 1.6% of seniors who gambled were at risk of addiction and 1.2% were already problem gamblers.⁴⁰⁵ In all of Canada, there are only 12 specialized addiction treatment programs serving approximately 1,250 seniors annually.⁴⁰⁶

⁴⁰¹ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁰² American Liver Foundation. Cirrhosis: Many Causes. Available at: <http://www.liverfoundation.org/db/articles/1059>.

⁴⁰³ Bradley, N. (September 2005) Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

⁴⁰⁴ *Ibid.*

⁴⁰⁵ Spencer, C. (June 2005) Alcohol and seniors: Gambling issues for seniors — Links, programs, research and resources. (June 2005) Available at: www.agingincanada.ca.

⁴⁰⁶ Spencer, C. (June 2005) Presentation to the Standing Senate Committee on Social Affairs, Science and Technology.

9.5.4 Children and Youth

Youth are most affected by mental health and addiction problems.⁴⁰⁷ Research has shown that early evidence of substance abuse in children and youth is a predictor of subsequent criminal behaviour.⁴⁰⁸ Some problem gamblers reported beginning to gamble as early as age 10.⁴⁰⁹ Children and youth are also vulnerable to emotional, physical and sexual abuse by substance-using caregivers.⁴¹⁰

Early evidence of substance abuse in children and youth is a predictor of subsequent criminal behaviour.

When it comes to early diagnosis...it is much easier to take care of the children before they get older. Early diagnosis...I know especially in addictions, can definitely save a life and a lifetime of heartache for not only the youth but so many others. —Dave Rodney⁴¹¹

Failing to address the impact of addiction and problem gambling in vulnerable populations, particularly youth, costs Canada a great deal in both human and economic terms. In a “pay me now or pay me later” scenario, the neglect of these groups is paid out over time in ever-rising social and health care costs.

Failing to address the impact of addiction and problem gambling in vulnerable populations, particularly youth, costs Canada a great deal in both human and economic terms.

Therefore, the Committee recommends (in addition to those recommendations specific to Aboriginal peoples in Chapter 14):

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| 43 | <p>That the Government of Canada conduct an assessment of the outcomes of existing programs dedicated to addiction problems for First Nations, Inuit and Métis peoples.</p> <p>That the results of this assessment be shared through the Knowledge Exchange Centre to be created as part of the Canadian Mental Health Commission (see Chapter 16) with a view to identifying successful treatment models and expanding these programs to improve access and reduce wait times.</p> |
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⁴⁰⁷ Statistics Canada. (2002) Canadian community health survey: Mental health and wellbeing. Available at: www.statcan.ca.

⁴⁰⁸ Dowden, C. (2003) The effectiveness of substance abuse treatment with young offenders. Available at: www.canada.justice.gc.ca.

⁴⁰⁹ Youth Gambling International. (2004) Youth problem gambling. Available at: www.education.mcgill.ca.

⁴¹⁰ Trocme, N., et al. (2005) Canadian incidence study of reported child abuse and neglect 2003: Major findings. Available at: www.phac-aspc.gc.ca/.

⁴¹¹ 9 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-c/soci-e/21eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

That the provinces and territories develop and implement evidence-based outreach, and primary and secondary prevention programs for at-risk populations — women, children and youth, seniors, and those affected by Fetal Alcohol Spectrum Disorders.

9.6 GOVERNMENT RESPONSIBILITY

Addiction must also be considered within the context of government regulation and taxation related to the sale of alcohol and the prevalence of gambling (including provincial lotteries), both of which are significant revenue sources.⁴¹² Powerful corporate interests are also involved in alcohol as well as gambling. Years of government inattention have left advocates frustrated by the low investment in

Years of government inattention have left advocates frustrated by the low investment in prevention, health promotion and treatment for people who have been harmed, relative to the large amounts of money collected in taxes and gambling profits.

prevention, health promotion and treatment for people who have been harmed, relative to the large amounts of money collected in taxes and gambling profits.⁴¹³

...we have to acknowledge the elephant in the room that no one seems to be tackling, which is that notwithstanding the need for looking at meaningful taxation processes for alcohol, volume content and the like, the government already collects a tremendous amount of revenue from this product and it is not earmarked for the right purposes. Although it may go to other good purposes, at the end of the day we should acknowledge openly that the government continues to encourage activities that they know will cause harm, such as gambling. —Michel Perron⁴¹⁴

9.7 NEW IDEAS THAT WORK

Notable strides have been made in helping people with addiction and mental health problems. These advances have been implemented in a number of locations in Canada and are showing either promising or positive results confirmed through research. They can be built upon to create a stronger, more integrated addiction and mental health system.

⁴¹² In 2002-2003, sales of alcoholic beverages totalled \$15.4 billion in Canada, with beer accounting for \$12.6 billion. Taxes on alcohol and tobacco accounted for 2.5% of all tax revenue. Source: Thomas, G. (2004) Alcohol-related harms and control policy in Canada. Available at: www.ccsa.ca. In 1999-2001, net government revenue from gambling — across Canada — equalled \$5.7 billion. Source: Canada West Foundation. (2001) Gambling in Canada 2001: Overview. Available at: www.cwf.ca. In 2001, the average Canadian household spent \$257 on government lotteries alone. Source: www.cbc.ca/background/gambling.

⁴¹³ Ontario Federation of Mental Health and Addiction Programs. (2003) Generating new revenue to support addictions services: A behavioural insurance model. Available at: www.ofcmhap.on.ca.

⁴¹⁴ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

9.7.1 Integrated Treatment for Concurrent Disorders

Substance abuse can mask the symptoms of a mental illness but, for those who are known to be mentally ill, it makes psychiatric symptoms worse. As a result, people with concurrent disorders⁴¹⁵ generally have more complex problems and are more difficult to help because they often exhibit more disruptive behaviours, are less accepting of treatment and are more prone to relapse⁴¹⁶ than those whose mental illness is not compounded by addiction or vice versa.

Both the mental health and addiction “systems” have been slow to acknowledge even the existence of concurrent disorders. Typically, people with them cycle back and forth as clinician-specialists try to decide which problem to treat first.

Both the mental health and addiction “systems” have been slow to acknowledge even the existence of concurrent disorders.⁴¹⁷ Typically, people with them cycle back and forth as clinician-specialists try to decide which problem to treat first.

When concurrent disorders have been recognized, treatment has tended to fall into one of three categories: *partial* treatment — focusing on one of the problems, assuming the other will abate over time; *sequential* treatment — starting with one problem and resolving it before treating the other; or *parallel* treatment — where separate services treat both problems at the same time.⁴¹⁸ The results have been less than satisfactory, primarily because of the disconnect between the two treatment systems and their differing philosophies. People just got lost.

Literature calls for *integrated* treatment – both problems are treated simultaneously by the same team, using compatible techniques and philosophies.

Literature on best practices recommends that mental health and addiction programs screen clients for both problems and, when problems are discovered, those affected should be fully assessed to ensure their proper treatment. It also calls for *integrated* treatment – both problems are treated simultaneously⁴¹⁹ by the same team, using compatible techniques and philosophies.⁴²⁰

⁴¹⁵ The term *dual diagnosis* is used in the United Kingdom and the United States.

⁴¹⁶ Stuart, H., on behalf of the Concurrent Disorders Champion Group. (2002) Concurrent disorders: An integrated service delivery plan for southeastern Ontario. (2002) Submitted to the Southeastern Ontario Mental Health Implementation Task Force and the Southeastern Ontario District Health Council.

⁴¹⁷ Rush, B. (undated) Concurrent mental and substance use disorders: Why is such “double trouble” so important? Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

⁴¹⁸ Negrete, J. (2003) Treating addiction in individuals with other mental illnesses. Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

⁴¹⁹ The one exception is that best practice guidelines (Rush, 2002) call for substance abuse to be treated first among people with mood and anxiety disorders — although integrated treatment is recommended for Post-traumatic Stress Disorder.

⁴²⁰ Centre for Addiction and Mental Health. (2002) Best practices: concurrent mental health and substance abuse disorders. Available at: www.cds-sca.com.

9.7.2 Community Reinforcement and Family Training (CRAFT)

The CRAFT approach is an alternative to some of the more confrontational interventions or strong tactics used by frustrated family members to persuade a loved one to enter treatment. It is a teaching model, most often accompanied by a workbook, in which aspects of cognitive behavioural therapy are employed to help families and friends develop ways to keep themselves safe, analyze under what circumstances substance abuse is most likely to occur, utilize positive reinforcements for both themselves and the addicted family member, and adopt healthier lifestyles. Research has shown that this minimalist intervention is highly effective in engaging in treatment people with addictions, including problem gambling; a 64% success rate has been achieved for people with drug and alcohol problems, and seven out of ten problem gamblers have been brought to treatment.⁴²¹

The more the family is involved, whoever they consider their family to be, the better they will do. —Nancy Bradley⁴²²

9.7.3 Harm Reduction

Harm reduction is intended to reduce the health and social impact of alcohol and drug use without asking that users abstain. Abstinence may be a long-term objective, but the short-term goal is to promote safe use. The features of harm reduction are: *pragmatism* — people are going to use drugs and alcohol and some will use them to excess; *humane values* — the dignity and rights of the user are respected; *focus on harm* — it's not how much a person is using, it's how much harm it is creating; and *hierarchy of goals* — the most important needs are attended to first.⁴²³

Harm reduction is intended to reduce the health and social impact of alcohol and drug use without asking that users abstain. Abstinence may be a long-term objective, but the short-term goal is to promote safe use.

9.7.3.1 Needle Exchange Programs (NEPs)

In Canada, the first unofficial needle exchange program (NEP) opened in Toronto in 1987. More were established officially in Toronto and Vancouver in 1989. Today there are 30 programs operating in Canada. All prisons administered by Correctional Service Canada provide bleach to inmates for needle sterilization, but despite repeated recommendations for the implementation of NEPs, no correctional jurisdiction in Canada provides sterile equipment to inmates.⁴²⁴

No correctional jurisdiction in Canada provides sterile equipment to inmates.

⁴²¹ Ontario Problem Gambling Research Centre. (undated) Minimal treatment approaches for concerned significant others of problem gamblers. Available at: www.gamblingresearch.org/printdoc.sz?cid=123.

⁴²² 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴²³ Thomas, G. (2005) Harm reduction policies and programs for persons involved in the criminal justice system. Canadian Centre on Substance Abuse. Available at www.ccsa.ca.

⁴²⁴ *Ibid.*

NEPs operate under an exemption in the Canadian *Criminal Code* and the *Food and Drugs Act* that makes the distribution of “drug paraphernalia” legal as long as the goal is to prevent HIV infection. Initially, the federal government shared the costs with provincial governments. Programs are now run under a variety of funding models, including federal and provincial/municipal partnerships. The cost of one needle exchange kit is slightly more than \$1.

Many fears regarding these programs have been expressed but, according to the evidence, have not materialized:

- Needle exchange programs do not lead to a proliferation of dangerous needles discarded in the community — in fact, more needles are turned in than given out.
- Needle exchange programs have not attracted drug dealers to the community where the site is located.
- Police do not object — the Canadian Association of Chiefs of Police has passed a resolution in favour of the National AIDS Strategy, including needle exchange programs.⁴²⁵

9.7.3.2 Supervised Injection Facilities (SIFs)

Supervised injection facilities (SIFs) include needle exchange but also offer safe places to use drugs and receive emergency medical care, basic health services, counselling, and referrals to other agencies, plus education and participation in social support networks among others living with addictions. SIFs typically have a number of house rules that relate to safety — for example, no alcohol, no violence, no “dealing,” local users only, and no one under 18 years of age.

The one SIF in Canada is in Vancouver. It functions as a scientific research project to be evaluated over three years. It was established under Section 56 of the *Controlled Drugs and Substances Act*, which allows the federal Minister of Health to issue an exemption from the provisions of the Act for specific medical or scientific purposes. Ninety percent of those who use the Vancouver SIF are Hepatitis C Virus positive, and 28-30% are HIV positive. Five hundred safe injections per day are provided at the site.⁴²⁶

9.7.3.3 Wine and Beer in Shelters

Some homeless people report that they will not enter shelters because they cannot bring their bottles with them; alternatively they binge just before entering, a cause of fights and injuries to staff and other residents. In

The program offers a glass of homemade wine once an hour, progressively diluted over time. Evaluation has shown fewer emergency room visits, hospitalizations and ambulance calls as a result.

⁴²⁵ Canadian Centre on Substance Abuse. (February 2004) Needle Exchange Programs (NEPs): FAQs. Available at: www.ccsa.ca.

⁴²⁶ Canadian Centre on Substance Abuse. (July 2004) Supervised injection facilities (SIF): FAQs. Available at: www.ccsa.ca.

response to violence in shelters and deaths on the street by freezing, staff in a few Toronto locations have started to introduce an approach to harm reduction that entails giving those living with alcohol addiction a drink of beer or wine every hour or two during their stay.

The Annex Harm Reduction Program, a satellite of St. Michael's Hospital in Toronto serving the men who live in Seaton House,⁴²⁷ now offers medical treatment and referrals to addiction treatment and housing. The preliminary results of an evaluation show that alcohol-related accidents and injuries are declining, that the men now drink safer forms of alcohol (instead of Lysol, mouthwash or rubbing alcohol), and that they receive better medical care. Some have reduced their drinking; others have entered treatment, while still others are in stable housing and have jobs.⁴²⁸

In Ottawa, the Shepherds of Good Hope Shelter has established a harm reduction program with a Supporting Community Partnerships Initiatives (SCPI) grant. It serves 10 people at a time, 24 hours a day, seven days a week and has a waiting list three times as long. The program offers a glass of homemade wine once an hour, progressively diluted over time. Evaluation has shown fewer emergency room visits, hospitalizations and ambulance calls as a result. Graduates of the program have obtained stable housing, stayed out of jail and entered treatment for addiction.⁴²⁹

9.7.4 Drug Treatment Court (DTC)

In 1998, the federal Department of Justice funded one drug treatment court (DTC) in Toronto and another in 2001 in Vancouver. These courts identify low-risk offenders whose main problem is drug abuse and who would benefit from treatment rather than time in jail. Offenders, including youth, are offered drug education, employment training and mental health treatment if they openly take responsibility for the offences they have committed. Sentencing is often confined to community service hours; alternatively, charges may be withdrawn if treatment is completed in a positive fashion. In May 2003, the federal government committed \$23 million over five years to expand DTCs.⁴³⁰

9.7.5 Day Detox and Home-Based Detox

The most cost-effective strategy for responding to early-stage alcohol problems is a single session of advice from a primary care physician with follow-up by a nurse.⁴³¹ Advances in research relating to detoxification services have shown also that people with physiological dependence on alcohol or drugs can enter a successful detox program that offers them

⁴²⁷ Seaton House is a shelter serving men.

⁴²⁸ Wysong, P. (November 2002) Homecare for the homeless. Medical Post, Vol. 38, Issue 40. Available at: www.medicalpost.com.

⁴²⁹ Alderson-Gill & Associates Consulting Inc. (2002) Evaluation prepared for the National Homelessness Initiative: Shepherds of Good Hope, Harm Reduction Program, Ottawa, Ontario. Available at: www.homelessness.gc.ca/projects/casestudies/docs/ottawa/shepherds_e.pdf.

⁴³⁰ Citizens for Mental Health Association. (2003) Background: Justice and Mental Health. Available at: www.cmha.ca/citizens/justice.pdf.

⁴³¹ Stockwell, T., assisted by Sturge, J. (September 2005) Brief to the Standing Senate Committee on Social Affairs, Science and Technology.

nursing support in their own homes or on a day program basis.⁴³² The idea of Community Alcohol Teams was developed in the United Kingdom and elsewhere because of long waiting lists for inpatient beds. Studies of the relative costs showed that hospital-based care cost roughly 10 times more than community care with little difference in outcomes.⁴³³ It should be noted, however, that homeless populations still require some form of residential detox service.

One example in the service I provided in the U.K is that we had one community nurse supervising as many home-based detoxifications for problem drinkers as the general hospital, which had been the other major service provider in the area, did in one year. —Tim Stockwell⁴³⁴

With the exception of the treatment of concurrent disorders and the CRAFT program, the emerging trends in this section remain controversial, particularly those related to harm reduction. Society judges harshly those it thinks have made bad choices. Harm reduction challenges perceptions because it is an adult-to-adult model that focuses on keeping everyone, including society as a whole, as safe as possible while preserving dignity and hope for those affected.

The most cost-effective strategy for responding to early-stage alcohol problems is a single session of advice from a primary care physician with follow-up by a nurse, nursing support in their own homes or on a day program basis

Given these advances, the Committee recommends:

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| 44 | <p>That the Government of Canada include as part of the Mental Health Transition Fund (see Chapter 16) \$50 million per year to be provided to the provinces and territories for outreach, treatment, prevention programs and services to people living with concurrent disorders.</p> <p>That family physicians be trained, through medical school and professional development curricula, on diagnostic guidelines for Fetal Alcohol Spectrum Disorders (FASD).</p> <p>That family physicians be trained in the use of brief intervention and interview techniques to recognize problem substance use leading to addiction.</p> |
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⁴³² Brunemeyer, N. (March 2004) Addictions services redesign at Vancouver Coastal Health. Four Pillars News, Vol. II, Issue 1. Available at: www.city.vancouver.bc.ca/fourpillars/newsletter.

⁴³³ Hayashida, M., Altman, A., McLellan, A., O'Brien, C., Purlil, J., Volpicelli, J., Pahelson, A., and Hall, C. (1989) Comparative effectiveness of inpatient and outpatient detoxification of patients with mild-to-moderate alcohol withdrawal symptoms. New England Journal of Medicine, Vol. 320, No. 6, pp. 358-365.

⁴³⁴ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

9.8 STEPS TO INTEGRATION

9.8.1 Build on Commonalities

Historically, mental health and addiction services have developed separately — each with its single focus. Addiction and mental illness are both enormously complex problems. Services for each must address a multiplicity of factors and contend with a host of personal and social consequences. Outcomes are uncertain even when the best of supports and treatments are in place. The two sets of services rest on differing philosophies relating to causes, effects and how to help. But there are signs of convergence, not the least of which are the emergence of literature on best practices and treatment of concurrent disorders, and the establishment of some joint services.

In my experience over the past 13 years, I have found that the “my turf” attitude has diminished to some degree. I have talked to people in the community who have said that there might be battles at the provincial level, but at the community level, everyone gets along fairly well. —Jeff Wilbee⁴³⁵

9.8.1.1 Recovery

Recovery has been a beacon of hope since the 1935 inception of the most famous self-help movement, Alcoholics Anonymous. Recovery is well defined in the addiction world — as a lifelong process of living well in the face of challenges. In the last 20 years, led by people living with mental illness, the mental health system has begun to embrace recovery⁴³⁶ as its defining concept. That concept, however, has yet to fully inform professional treatment philosophies.

9.8.1.2 Self-Help and Peer Support

Although founded on self-help, addiction services have been professionalized over time. Substance abuse specializations have developed in higher learning centres, together with professional accreditation and certification. Most addiction services now have strong professional leadership. The modern mental health system began with a medical specialty, psychiatry, that, over the last century, has spawned a number of other mental health professions such as psychiatric nurses and social workers. Relatively speaking, the self-help movement in mental health is new and has had to advocate strongly for its place in the largely professionally driven system. Happily, providers in both addiction and mental health services have

Recovery is well defined in the addiction world — as a lifelong process of living well in the face of challenges. In the last 20 years, led by people living with mental illness, the mental health system has begun to embrace recovery as its defining concept.

The self-help movement in mental health is new and has had to advocate strongly for its place in the largely professionally driven system.

⁴³⁵ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴³⁶ See Chapter 3 for a fuller discussion of how “recovery” is defined within the mental health system.

come to understand and value self-help and peer support, while still acknowledging the need for a professional presence.

We still have peer professionals, and I do not think anyone can provide a sense of hope for change for a consumer group better than people who [have] gone through the system themselves. I do not think anyone can navigate or advocate better. There will always be a place for that, but the ratio is changing [peer support versus professional care] because of the type of service we are delivering.
—Greg Purvis⁴³⁷

9.8.1.3 Non-Medical Community-Based Services

Addiction services, evolving out of self-help, have a historical commitment to a community-based, non-medical approach. While individuals must, from time to time, seek medical interventions and/or psychiatric assessment, diagnosis and medication, it may be said that, as a whole, services for people with addictions are intent upon remaining non-medical in nature and community-based.

Addiction services, evolving out of self-help, have a historical commitment to a community-based, non-medical approach.

Community mental health services evolved as a result of the deinstitutionalization that began in the late 1960s.

Community mental health services evolved as a result of the deinstitutionalization that began in the late 1960s. Throughout Canada, governments have continued to close psychiatric inpatient beds. Although investment in community services has been too slow to materialize, the commitment from policy makers and from the field to building a system based mainly on non-medical community supports and services is solid.

9.8.1.4 Broader Determinants of Health

Community mental health services evolved as a result of the deinstitutionalization that began in the late 1960s. Managers and providers of mental health and addiction services are deeply aware of the importance of broader health determinants in preventing problems in the first place, and/or in lessening the effects of problems once they emerge. Safe and affordable housing, employment, education, adequate income supports, and freedom from violence are crucial to the health and well-being of all Canadians; they are life-sustaining for people living with mental illness and addiction.

9.8.1.5 Early Intervention

Identifying problems early, and then intervening in the least disruptive and life-altering manner possible, is acknowledged by both service sectors as crucial. Healthy pregnancies, assisting at-risk parents to acquire skills, a focus on early childhood development, and helping

Early intervention in psychosis is perhaps the most hopeful integrative treatment approach to emerge in mental health.

⁴³⁷ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

children and youth with emerging substance abuse problems, all save lives and/or prevent a lifetime of dependence on a variety of expensive health and social programs.

Early intervention in psychosis is perhaps the most hopeful integrative treatment approach to emerge in mental health. Young people at risk, identified early and given lower doses of medication over shorter periods of time, can avoid hospitalization, loss of education, unemployment, and the loss of social and family supports.

Senator, you asked about pieces that are missing. What struck me immediately was the number of times I have read and heard presentations at conferences about childhood trauma, abuse and addiction. What I am about to say is not just about how to improve the treatment system but how to decrease the demand for the treatment system. An increased effort to deal with damaged children will have as much impact on the addiction treatment system as anything done directly in the addiction treatment system. —Jon Kelly⁴³⁸

Competition between the addiction and mental health care sectors for scarce resources makes no sense. It only entrenches differences and discourages collaboration. However, there is reason to believe that numerous commonalities have emerged over time. It is now time for addiction and mental health services to begin to build integrative mechanisms based upon their shared interests, views and, above all, the benefits to affected people that will accrue.

Competition between the addiction and mental health care sectors for scarce resources makes no sense. It only entrenches differences and discourages collaboration.

9.8.2 A Step-by-step Approach

British Columbia's policy document entitled *Every Door is the Right Door* proposes to develop a collaborative model of health system responses that spans the domains of population health, health promotion, harm reduction and building community capacity. The model is intended to assist local health authorities to plan, implement and evaluate an integrated and evidence-based system for people with addictions and mental illness.⁴³⁹

British Columbia's policy document entitled *Every Door is the Right Door* proposes to develop a collaborative model of health system responses that spans the domains of population health, health promotion, harm reduction and building community capacity.

Alberta's document, *Building capacity: A framework for serving Albertans affected by addiction and mental health issues*, aims to improve access and services for people with concurrent disorders through service partnerships and shared care, typically psychiatrists providing consultation to

⁴³⁸ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴³⁹ British Columbia Ministry of Health Services. (May 2004) *Every door is the right door: A British Columbia planning framework to address problematic substance use and addiction*. Available at: http://www.healthservices.gov.bc.ca/mhd/pdf/framework_for_substance_use_and_addiction.pdf.

primary care physicians. The framework also emphasizes information, prevention and early intervention for those whose conditions are not yet severe.⁴⁴⁰

[The CCSA] position is quite clear. We fully support a new model for the coordinated delivery of mental health and addiction services to Canadians, and we believe that where appropriate, such a model requires a careful and strategic integration of approaches to treatment of mental health problems and addictions. —Michel Perron⁴⁴¹

Alberta's document, *Building capacity: A framework for serving Albertans affected by addiction and mental health issues*, aims to improve access and services for people with concurrent disorders through service partnerships and shared care, typically psychiatrists providing consultation to primary care physicians.

9.8.2.1 The Quadrant Model

This model is well-known among service providers in the addiction field. It has been endorsed as a “thinking tool” that helps conceptualize integration in a way that respects the differences between the mental health and addiction fields while, at the same time, offering opportunities for integration that can be acted upon fairly swiftly.⁴⁴²

| | | | |
|--|-----------|--|--|
| A D D I C T I O N | ↑ High | Quadrant 3 A high level of addiction problems with a low level of mental illness SPECIALIZED ADDICTION CARE | Quadrant 4 A high level of addiction problems with a high level of mental illness SPECIALIZED INTEGRATED CONCURRENT DISORDER CARE |
| | ↓ Low | Quadrant 1 A low level of addiction problems with a low level of mental illness PRIMARY CARE | Quadrant 2 A low level of addiction problems with a high level of mental illness SPECIALIZED MENTAL HEALTH CARE |
| | | ← Low | High → |
| | | MENTAL ILLNESS | |

People with a combination of a low level of mental health and addiction problems (Quadrant 1) are by far the largest segment of society who will seek help most frequently from a primary care physician. The quadrant model proposes that addiction and mental health services become *concurrent disorder capable*, meaning that those services must be able to

⁴⁴⁰ Alberta Alcohol and Drug Abuse Commission. (July 2005) Building capacity: A framework for serving Albertans affected by addiction and mental health issues. Available at: www.aadac.com.

⁴⁴¹ 21 September 2005, http://www.parl.gc.ca/38/1/paribus/commbus/senate/Com-c/soci-e/28ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁴² Skinner, W. (September 2005) Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

recognize and respond to both mental health and addiction problems. Only those who fall into Quadrant 4, the number of whom is not large, require *concurrent disorder specialized services*.

The quadrant model does not value one service system over another. Nor does it presuppose the amalgamation of administration and services over the two fields, or the elimination of specialized programs. Integrative mechanisms could be built locally to include: service agreements among mental health and addiction agencies; designation of local “lead” organizations that take on the role of intake, assessment and referral; communication tools that facilitate the secure exchange of personal health information; and the use of distance technology to bring mental health, addiction and specialized services to remote or under-served areas.

9.8.2.2 A Shared National Focus

The addiction field has had the benefit of a National Drug Strategy (May 2003), a national survey of Canadians’ use of alcohol and drugs (the *Canadian Addiction Survey*, November 2004) and the ongoing leadership of the Canadian Centre on Substance Abuse. A National Framework for Action on Substance Use and Abuse is currently being created through a broad consultation process culminating in a national addiction conference held in June 2005.⁴⁴³

On 7 June 2005, the House of Commons passed a motion calling for, among other things, a national strategy on mental health.⁴⁴⁴ This motion paves the way for the creation of a National Mental Health, Mental Illness and Addiction Strategy which must incorporate, but not subsume, ongoing national activities in the field of addiction.

9.8.2.3 Taking the Long View

The experience in other jurisdictions where integration has begun shows that it is a difficult process despite the commitment of people in the field. Creating a closer relationship between the addiction and mental health systems will take time, leadership and money, but the first steps must be taken without delay.

The preferred approach to integration is to preserve that which is unique in each field, while building on common values, dialogues and obvious points of agreement.

⁴⁴³ The National Framework has identified: Issues (increasing awareness of problematic substance abuse, reducing the problematic use of alcohol, preventing the problematic use of pharmaceuticals, addressing enforcement strategies and addressing Fetal Alcohol Spectrum Disorder); Supportive Infrastructure (sustaining workforce development, increasing access to services, implementing a national research agenda along with knowledge transfer, and modernizing legislation, regulatory and policy frameworks); and Key Populations (children and youth, people of the North, First Nations, Inuit and Métis, and offenders).

⁴⁴⁴ The motion reads as follows: “That, given a national strategy is needed now to reduce the growing human and economic costs of cancer, heart disease and mental illness; the House call on the government to fully fund and implement the Canadian Strategy for Cancer Control in collaboration with the provinces and all stakeholders, and given that Canada is one of the few developed countries without a national action plan for effectively addressing mental illness and heart disease, the government should immediately develop and initiate a comprehensive national strategy on mental illness, mental health and heart disease” [emphasis added].

If people have the freedom to talk, discuss and disagree on the process and work their way through it, then that will breed far more grassroots buy-in. [...] Once the awareness-raising happens, and people begin to get their heads around it, we will need resources and opportunities for them. Without those, it would be much ado about nothing. The resources must be available in your back pocket before you step forward into consciousness-raising. Otherwise, you are setting people up to disagree, and for it not to happen. Also, you need to build in outcomes, measure the outcomes, and feed them back to the field. Nothing will increase the buy-in more in the field of mental health and addictions for a change in process than positive outcomes. People want to succeed and do well by their clients. —Greg Purvis⁴⁴⁵

Addiction services in Canada are fragmented and chronically under funded, resulting in inadequate responses to the needs of those living with addiction and their families. The culture of separateness between mental health and addiction services has added to the frustration. But a number of important commonalities can be utilized as logical starting points for integration. Committee members were told that the preferred approach to integration is to preserve that which is unique in each field, while building on common values, dialogues and obvious points of agreement.

Therefore, the Committee recommends:

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| 45 | That the Canadian Mental Health Commission (see Chapter 16) actively partner with national addiction organizations, and work toward the eventual goal of integration of the addiction and mental health sectors. |
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9.9 CONCLUSION

Advances in scientific knowledge have produced interventions that show positive results for people with addictions. The Committee's witnesses emphasized particularly the need for integrated treatment for people with both mental health and addiction problems — concurrent disorders. We support this direction.

The Committee's witnesses emphasized particularly the need for integrated treatment for people with both mental health and addiction problems — concurrent disorders.

We call for sustained investment to mitigate the effects of the misuse of legal substances on the health and well-being of Canadians.

Testimony was notably absent from people living with addictions, and from their families. The Committee commends for their courage those who did step forward. We are committed to building a strong consumer and family presence within the addiction sector.

⁴⁴⁵ 21 September 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/28ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Testimony before the Committee made overwhelmingly clear the problems associated with addictions to legally available substances coupled with long waits for help. We call for sustained investment to mitigate the effects of the misuse of legal substances on the health and well-being of Canadians.

Gambling is a significant revenue source for governments, but many people are gambling at problem levels and are not seeking treatment in the numbers expected. This hidden problem is only beginning to emerge; it must not be ignored, nor must its lack of visibility lead to a false sense of complacency. Governments must help those who are harmed by gambling.

Governments must help those who are harmed by gambling.

The Committee was persuaded by arguments in favour of harm reduction.

The Committee was persuaded by arguments in favour of harm reduction. These varied approaches, which have been demonstrated to relieve suffering, have often been developed by direct services workers who use their ingenuity to solve the problems they and their clients face daily.

The Committee calls for effective outreach and prevention strategies focused specifically on those who are most at risk.

Vulnerable populations — Aboriginal peoples, youth, seniors and women — suffer disproportionately from the effects of addiction and problem gambling. We were particularly affected by the preventable tragedy of Fetal Alcohol Spectrum Disorders. The Committee calls for effective outreach and prevention strategies focused specifically on those who are most at risk.

The Committee was impressed with the level of agreement among witnesses in support of the eventual integration of the mental health and addiction sectors. We heard that the differences and debates that can preoccupy service providers and policy makers do not make much sense to people with addictions and their families. All they want is help — now. Fortunately, the Committee heard that there are many points of agreement between addiction and mental health services that can be built upon as integrative mechanisms.

10.1 INTRODUCTION

Self-help provides emotional support and practical help. It is the kind of help you cannot duplicate in a doctor's office. No one can say better than somebody living with, through and beyond a mental illness, "I understand how you feel. I am on a quest for recovery with you." —Linda Bayers⁴⁴⁶

Over the course of its extensive public hearings, the Committee heard regularly from people living with mental illness or addiction, and their families, who are disappointed by their lack of access to services and disheartened by the paucity of hope that they feel characterizes mental health and addiction care in Canada. While acknowledging that professional help is valuable, people and families living with mental illness are turning more and more to self-help and peer support as a substitute for, or as an adjunct to, hospital, community and professional services.

People and families living with mental illness are turning more and more to self-help and peer support as a substitute for, or as an adjunct to, hospital, community and professional services.

The best-known self-help program is Alcoholics Anonymous (AA), which began operation in 1935. Only a few years later (1937), Abraham Low, a physician, founded Recovery Inc., focused specifically on the needs of people with mental illness, headquartered in Chicago. Today, it maintains its strictly volunteer tradition all over North America (www.recovery-inc.org). Similarly, GROW, founded in Sydney, Australia, in 1957, supports thousands of members based on its version of a 12-step program and a philosophy of “caring friendship and mutual help” (www.grow.net.au).

In Canada, the first alternative mental health service based on people living with mental illness helping one another, called the Vancouver Mental Patients' Association (MPA), was established in 1971. It remains in operation (now calling itself Motivation, Power and Achievement - MPA) (www.vmpa.org).

⁴⁴⁶ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

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National Peer Support Program for current and former Canadian Forces Members (www.ossis.ca). This unique program, launched in February 2002, is part of the Operational Stress Injury Social Support Project. It has served 1400 individuals and family members since opening, with referrals coming at a pace of one per day. Across 12 sites, it employs 20 trained Peer Support Workers, each of whom has experienced a stress injury. A professional team is available for consultation if required. Family members have six sites across the country. The role of the Peer Support Workers is two-fold: To help others heal from an operational stress injury and to pay attention to their own self-care. This non-medical model has been presented to audiences in Canada, Australia and Berlin. The program's goal is "to provide the best possible peer support to the men and women of the Canadian Forces, who continue to participate in an ever-growing number of demanding operations around the world" (General Ray Henault, Chief of Defence Staff, 2002). Says Lt. Colonel Stéphane Grenier, Project Director, "Peer support saves lives everyday."

10.2 THE MOTIVATIONS BEHIND SELF-HELP AND PEER SUPPORT

People living with mental illness, and their families, point to the many negative messages from society and from professional caregivers that impede healing and recovery.

In today's society, the stigma of mental illness plagues us still. We feel this stigma everyday of our lives... from being overlooked for promotion at work... to being harassed by medical insurance companies who question the validity of our illnesses so they no longer have to pay disability benefits... to sitting in emergency waiting rooms for hours on end, sometimes leaving in despair... because we are not high priorities.
—Frank Dyck⁴⁴⁷

10.2.1 Finding a Place to Belong

People living with mental illness say that the most devastating impact on their lives came not from the illness itself but from the way others began to treat them. Prejudice and discrimination take many forms: disregard for the person's rights, ostracism, loss of friends, sometimes rejection by family members and, in many instances, loss of housing and employment. Thirty-four percent of respondents participating in the Committee's e-consultation reported that they or others they knew had been turned down for a job or fired because of a mental illness, and 21% had been denied housing by a landlord.⁴⁴⁸

People living with mental illness say that the most devastating impact on their lives came not from the illness itself but from the way others began to treat them.

⁴⁴⁷ Dyck, F. (2 June 2005) Speaking notes prepared for hearings of the Standing Senate Committee on Social Affairs, Science and Technology.

⁴⁴⁸ Chodos, H., N. Pogue and T. Riordan. (2005) E-consultation on mental health, mental illness and addiction: Phase one. Parliamentary Information and Research Service, Library of Parliament.

We know when we break a leg we go to the emergency room. But if we are having a panic attack or thinking of harming ourselves, we don't know where we should go. We are told to go to the emergency room, but they see no wounds and we are dismissed. —Anonymous

Families also bear the brunt of stigma. Making matters worse, people and families living with mental illness may internalize these negative social attitudes and blame themselves for their own marginalization. People living with mental illness state that there is also “prejudice and discrimination in the mental health system itself” — the system to which they turn for help when they are most vulnerable.⁴⁴⁹

Families also bear the brunt of stigma.

Two-thirds of people suffering from addiction or mental illness simply do not seek help.

Twenty-two percent of respondents to the Committee's e-consultation reported that they had been treated with disrespect by medical personnel or had a physical ailment ignored because of their mental illness or addiction.⁴⁵⁰

Self-help and peer support counteract stigma by providing people a place where they are safe and welcome.

Not surprisingly, research shows that two-thirds of people suffering from addiction or mental illness simply do not seek help.⁴⁵¹

Self-help and peer support counteract stigma by providing people a place where they are safe and welcome. This is particularly important for client groups that have been poorly served by the mainstream mental health system:

Over time, it became clear that it might not be possible, and perhaps not even desirable, to promote cultural sensitivity within the conventional mental health service providers, with a view to these agencies at some point undertaking the responsibility to deliver this type of healing alternative. [...] [Healing circles] are rooted in ceremonies and traditions that can only be performed by those from the Aboriginal community who possess a depth of knowledge and who are recognized within that community as being capable of leading healing circles.

[...]

Over the life of the project... the majority [of clients] use the healing circles alone as their preferred method of recovery. —Tarry Hewitt⁴⁵²

⁴⁴⁹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 3, Section 3.4.1, p. 59 (Quote from Jennifer Chambers' testimony).

⁴⁵⁰ Chodos, H., N. Pogue and T. Riordan. (2005) E-consultation on mental health, mental illness and addiction: Phase one. Parliamentary Information and Research Service, Library of Parliament.

⁴⁵¹ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 3, Section 3.2.1, p. 42 (Quote from Rena Scheffer's testimony).

⁴⁵² 16 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

10.2.2 Counteracting the Powerlessness of the Patient/Client Role

The Committee was told that playing the role of patient or client is debilitating in itself because the focus is on illness and disability.⁴⁵³ Being dependent on help from those who claim exclusive expertise and who, by definition, are in a superior position, further erodes the self-esteem of the person who is defined as the patient or client as well as their ability to act effectively in their own interests. Over time, people can lose hope and fully embrace passivity. Experience has taught them that their views are unwelcome, someone else knows better, and it is easier (and in some instances, safer) to cease to struggle and let others make decisions.

It is very hard to ignore [professional] feedback or to put it aside as just one person's opinion when it comes from a health professional, and it is really hard to stand up in the face of authority and say, "I want more,"...particularly because you are a mental patient... —Helen Hook⁴⁵⁴

10.2.3 Finding Hope in a Sea of Hopelessness

People living with mental illness have often been told that they will not complete their education and will never hold a job or work. For many years, researchers characterized mental illness as generating an inevitable downward spiral — both in function and in social status. The prognosis was bleak: permanent disability, isolation and poverty.

The opinions of people living with mental illness have too often been reinterpreted as a manifestation of denial or as “part of the illness,” disallowing them a credible role in their own care and life decisions.

The opinions of people living with mental illness have too often been reinterpreted as a manifestation of denial or as “part of the illness,” disallowing them a credible role in their own care and life decisions. Pejorative labels such as non-compliant, manipulative, difficult to direct, hard to serve, attention-seeking or interfering (for family members) have discredited assertive behaviours and have further silenced people.

People living with mental illness state that their expression of healthy human emotions such as sadness, fear and anger is often medicated as opposed to validated.

People living with mental illness state that their expression of healthy human emotions such as sadness, fear and anger is often medicated as opposed to validated.⁴⁵⁵ The elements of human growth and pleasure are transformed into therapeutic interventions, such as bibliotherapy, art therapy, music therapy, horticultural therapy, interpersonal relationship therapy, and social network therapy, etc. These interventions may be helpful but they constitute professionally mediated encounters that recast normal activities in terms of treatments.

⁴⁵³ Mead, S., D. Hilton, and L. Curtis. (Undated) Peer support: A theoretical perspective. Available at: www.mentalhealthpeers.com.

⁴⁵⁴ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁵⁵ Everett, B. (2000) Consumers and psychiatric survivors confront the power of the mental health system. Waterloo, ON: Wilfrid Laurier University Press.

The range of supports that currently exist for those who are deemed unable to work includes a monthly pension with subsidized medications, subsidized housing for the fortunate, and a support network of health professionals and programs for free. I would suggest that many individuals are trapped and left unmotivated to plan and execute an exit strategy from this cycle of learned helplessness. —Raymond Cheng⁴⁵⁶

10.2.4 An Antidote for Identity Theft

Persons living with mental illness are asked to accept their diagnosis as reality and to develop insight into their illness and disability, so much so that they feel their identities as parents, siblings, employees, students, athletes, artists — as individuals — are erased or, at the least, diminished. People are spoken of as addicts, schizophrenics or depressives. They have *become* their illness.⁴⁵⁷

People are spoken of as addicts, schizophrenics or depressives. They have become their illness.

Some argue that their personhood has been invaded, conquered and colonized in much the same way countries have been defeated and occupied by a foreign power.

10.2.5 Reclaiming One's Own Story

People and families living with mental illness often have to tell their stories over and over again to a variety of disconnected professionals.⁴⁵⁸ Even more problematic is loss of control over their own histories. Many feel that reinterpretation of their experiences in the unfamiliar language of medical or rehabilitation terminology does not describe adequately the personal reality of that experience. These “translations” can overlook the context of their lives, concentrating on their conditions rather than acknowledging what is wrong with their individual situations.⁴⁵⁹ Experiences of abuse, racism, oppression, marginalization, homophobia, sexism, childhood trauma, violence in relationships, loss and grief, poverty, bullying, unemployment and other stressful life circumstances can be ignored or, if included in the “translation,” fail to lead on to interventions that take them into account. Positive factors such as a supportive family, a particular talent, or dedication to culture and community can also be missed when the “translator” concentrates narrowly on assessment, diagnosis and medication.

⁴⁵⁶ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁵⁷ Estroff, S. (1989) Self, identity and subjective experiences of schizophrenia: In search of a subject. *Schizophrenia Bulletin*, Vol. 15, No. 2, 189-196.

⁴⁵⁸ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 1, Section 1.1.1, p. 8 (Quote from Loise Forest's testimony).

⁴⁵⁹ Mead, S., and C. MacNeil. (2004) Peer Support: What makes it unique? Available at: www.mentahealthpeers.com.

In the course of my work, I hear stories of abuse, abuse perceived in the eyes of patients and I feel the force of their outrage at how they have been treated.
—Ron Carten⁴⁶⁰

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The Dream Team (Toronto) (www.thedreamteam.ca). The team is made up of persons living with mental illness, and their families, who distilled their personal stories into three-minute speeches delivered to politicians, community groups, universities and anyone who will listen to their message — safe, affordable housing saves lives. The group books presentations for a fee and its goal, aside from getting the central message across in an entertaining and moving way, is to validate consumers' and families' life stories.

10.2.6 Meeting the Need for Information

Accurate and complete health and service information is essential to the role of full partner in one's own care or that of a loved one. People living with mental illness, and their families, have told the Committee that they lack access to even the most basic information. For example, 33% of respondents to the Committee's e-consultation said services could be improved simply if more information was made available.⁴⁶¹ Sixty-six percent of families identified information as a pressing need.

People living with mental illness, and their families, have told the Committee that they lack access to even the most basic information.

People and families living with mental illness believe there is no substitute for conversations with a peer and exchanges of information among those who have "been there."

What does a diagnosis of mental illness mean? What will the medications do? Where can I get community services? How do I get help for a loved one with an addiction? What are my rights?

Rushed professionals may offer few answers or communicate in a way that is hard to understand. As a result, people and families living with mental illness believe there is no substitute for conversations with a peer and exchanges of information among those who have "been there."

...if you have a health problem, go to a self-help group. You will find out information because self-help group members are information junkies surfing the Internet day and night for information on how to get better and how to recover. They provide emotional support and practical help. They are cheerleaders. They say, "You can do it because I did it." Where else can you

⁴⁶⁰ Carten, R. (June 2006) Submission to the Standing Senate Committee on Social Affairs, Science and Technology.

⁴⁶¹ Chodos, H., N. Pogue and T. Riordan. (2005) E-consultation on mental health, mental illness and addiction: Phase one. Parliamentary Information and Research Service, Library of Parliament.

do that when you are feeling hopeless? There is no place else on planet earth where you can get that kind of help. —Linda Bayers⁴⁶²

The Committee recommends:

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| 46 | <p>That programs be put in place to develop leadership capacity among persons living with mental illness, and their families.</p> <p>That the Knowledge Exchange Centre (see Chapter 16) contribute to building this capacity by facilitating electronic access to information and technical assistance for people affected by mental illness and their families.</p> |
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10.2.7 Having a Voice

People with experience of the mental health system frequently report that they are the voice least heard, both as individuals and at the systems level. Advocacy means “to give voice to.” That is the fundamental purpose of a number of self-help organizations speaking on behalf of people who are or have been in the mental health or addiction system. Having a say in matters that most affect you is essential to everyone’s sense of well being and citizenship. Groups that are entirely made up of the people for which they speak are uniquely empowering. They constitute a vital resource for communities that typically are talked about but seldom talked to.

10.2.8 Finding Recovery

The hopeful and optimistic concept of recovery⁴⁶³ has emerged from the consumer movement and in response to negative treatment experiences in the formal mental health and addiction system. Utilizing experiential knowledge hard won through their own struggles, people living with mental illness have initiated a new dialogue that has begun to influence government policy and is slowly making its way into professional literature. Self-help and peer support groups are the incubators of individual recovery and a key sustaining force behind the broader acceptance of recovery as the guiding principle for all that occurs in the formal system.

Self-help and peer support groups are the incubators of individual recovery and a key sustaining force behind the broader acceptance of recovery as the guiding principle for all that occurs in the formal system.

10.2.9 Summary

Professionally defined identities based on illness and disability can overwhelm individuality and become the way persons living with mental illness, and their families, are known — by

⁴⁶² 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁶³ See Chapter 3, Section 2, for a full discussion of “recovery.”

caregivers, by society, by the media and by themselves. Social and systemic forces coalesce to present them a bleak future — unproductive, lonely and hopeless. Self-help supports the concept of recovery and responds to the full tapestry of people’s individuality. Illness is only one part — perhaps even the smallest part — of a rich life fully worth living.

10.3 SELF-HELPER AND PEER SUPPORT IN CANADA

Self-help constitutes people helping people — those who have “been there” sharing the common experiences of life-transforming events. A primary benefit of self-help is affiliation, “the great relief of knowing you are not alone.”⁴⁶⁴ In Canada, self-help and peer support have evolved in three ways.

A primary benefit of self-help is affiliation, “the great relief of knowing you are not alone”.

10.3.1 Volunteer Organizations

Historically, self-help organizations have not received formal funding. The members have themselves defined the ways in which they support and sustain each another. Self-help or mutual aid (as it is also known) is based on the defining feature that all members are equal — all are experts on their own lives, no one knows more than anyone else and no one has all the answers.⁴⁶⁵ Individual life experiences are the “knowledge base,” and encouragement and hope the “methodologies” by which empowerment occurs and healing takes place.

Peers will likely have attended orientation or training programs to equip themselves with basic information on how to be most helpful; but they are volunteers, spending their own time with others whose journey, they hope, will be made easier by their presence.

Peer support is when a group of individuals who have experienced the mental health system come together regularly in a safe and comfortable environment to share each other’s stories, be empathetic, and take the time to understand people. —Raymond Cheng⁴⁶⁶

Peer support is also a form of self-help that includes one-to-one relationships between people who have had similar experiences. Like self-help, it is a system of “giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful.”⁴⁶⁷

Peers see one another as individuals with stories to tell, rather than as “patients,” “clients,” or “cases” to be managed.⁴⁶⁸ Peers may be further along in their own recovery than those

⁴⁶⁴ Everett, B. (ed). (1994) You are not alone: A handbook for facilitators of self help and mutual aid support groups. Available through: Mood Disorders Association of Ontario.

⁴⁶⁵ Clay, S. (ed). (2005) On our own together: peer programs for people with mental illness. Nashville, TN: Vanderbilt University Press.

⁴⁶⁶ 17 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁶⁷ Mead, S., D. Hilton, and L. Curtis. (undated) Peer support: A theoretical perspective. Available at: www.mentalhealthpeers.com.

⁴⁶⁸ Canadian Mental Health Association, Ontario, the Centre for Addiction and Mental Health, the Ontario Federation of Community Mental Health and Addiction Programs and the Ontario Peer

they help — but mutuality of experience is always foremost. They spend time with the newly diagnosed, the freshly discharged and those in crisis. They offer information, resources and the reassurance that comes from sharing their own stories.

In preparation for their role, peers will likely have attended orientation or training programs to equip themselves with basic information on how to be most helpful; but they are volunteers, spending their own time with others whose journey, they hope, will be made easier by their presence.

We stress that we are not professionals but people who have lost a loved one through the act of suicide. Through our own stories, we help others share their grief and find a path to recovery. —George Tomie⁴⁶⁹

10.3.2 Paid Peer Support

Some peer support workers are para-professionals employed by mainstream mental health or addiction service providers (hospital or community-based) working in Assertive Community Treatment (ACT) teams or outpatient counselling programs. Others may work in non-medical, community-based environments as staff hired for the life experiences that qualify them for the job, not for their professional expertise and qualifications.

Paid peer support workers can have many titles — Peer Advocate, Peer Counsellor, Peer Tutor, Case Manager Aid, System Navigator, Consumer Advisor, Peer Outreach Worker (www.mentalhealthconsumer.net) — the variety is bounded only by the limits of imagination. Unlike volunteers, they have been formally trained in the role. Many peer support programs include peers as members of mobile crisis teams and staff in safe houses and have been established out of the need to deal with psychiatric crises out-of-hospital.⁴⁷⁰

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The Gerstein Centre is a 24-hour non-medical crisis centre located in downtown Toronto. It hires people based on life experiences to provide mobile crisis services, short-stay safe house residential care and telephone crisis counselling. Its philosophy: the environment and support offered are individualized, responsive to the needs and wishes expressed by the service user, and respectful of the autonomy, dignity and ability of the service user. It is the oldest program in Canada of its type and, this year, celebrates its 15th anniversary.

Development Initiative. (March 2005) Consumer/survivor initiatives: Impact, outcomes and effectiveness. Available at: www.ofcmhap.on.ca.

⁴⁶⁹ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁷⁰ Mead, S., and D. Hilton. (2003) Crisis and connection. *Psychiatric Rehabilitation Journal*, Vol. 27, No. 1, 87-94.

10.3.3 Paid Peer Support Workers in Stand-Alone Consumer and Family Organizations

In 1991 the Ontario government established the Consumer/Survivor Development Initiative (CSDI) with an initial investment of \$3.1 million (now \$4.5 million). CSDI has since evolved into the Ontario Peer Development Initiative (OPDI). The philosophy that underpins the program is one of peer-to-peer support.

These funded organizations were not to provide such services as counselling or case management in the way professional organizations did, but to build upon the culture of mutuality and experiential knowledge that is at the centre of self-help. The resulting Consumer Survivor Initiatives (CSIs) employ peers in roles that include economic or community development, one-to-one peer support, social activities, peer education, advocacy and website communications.

PROFILE

The Ontario Peer Development Initiative (www.opdi.org) (OPDI) evolved from the Consumer/Survivor Development Initiative in response to the need, expressed by CSIs, for technical support. The organization offers assistance in board and organizational development, conflict resolution, along with membership and resource development.

10.3.4 Summary

In Canada, as elsewhere, self-help and peer support programs have grown in an *ad hoc* fashion. Although some have been funded by governments, most exist independently of one another on shoestring budgets and struggle for survival. But survive they do — on passion, commitment and dedication. Paid peer support has emerged in isolated pockets supported by provincial/territorial funding. As a new and tenuous addition to the mental health and addiction system, the future of self-help and peer support programs remains insecure.

The Committee recognizes the value of self-help and peer support organizations and is aware of the financial difficulties facing many such organizations across the country.

We believe that the largest group of service providers are families, and that self-help groups are a significant support to persons with mental illness. Self-help groups have demonstrated their effectiveness in Manitoba. They are adjuncts to the mental health professionals for both patients-clients and families.

Self-help groups must continue to be part of the system and spend their time assisting their members, as opposed to spending time and resources in fundraising. Services should be devolved to them. Their individual approaches must be protected. —Annette Osted⁴⁷¹

⁴⁷¹ 31 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

The Committee recognizes the value of self-help and peer support organizations and is aware of the financial difficulties facing many such organizations across the country. Therefore, the Committee recommends:

47 **That funding be made available through the Mental Health Transition Fund (see Chapter 16) that is specifically targeted at:**

- **Increasing the number of paid peer support workers in community-based mental health service organizations.**
- **Providing stable funding to strengthen existing peer development initiatives, build new initiatives (including family groups), and build a network of self-help and peer support initiatives throughout the country.**

That the federal government lead by example, building on innovations such as the National Peer Support Program for current and former Canadian Forces members and support, with appropriate levels of funding, self-help and peer support programs for the client groups that fall under the jurisdiction of the federal government.

10.4 RESEARCH INTO SELF-HELP AND PEER SUPPORT

Testimony from persons living with mental illness, and their families, credits self-help and peer support for being effective and, in many cases, virtually life-saving.

I have no shame. I owe my life to the OSISS group (Operational Stress and Injury Social Support). —Corporal Clement⁴⁷²

Studies that evaluate the effectiveness of self-help and peer support are emerging. The research that is available has tended to be descriptive or has surveyed members' satisfaction.⁴⁷³ But in the United States, an evolving body of research documents the outcomes of peer support programs,⁴⁷⁴ and there are some recent Canadian studies noteworthy for their scientific rigour.

Testimony from persons living with mental illness, and their families, credits self-help and peer support for being effective and, in many cases, virtually life-saving.

Nelson *et al.* examined four Consumer Support Initiatives in Ontario offering educational events, advocacy opportunities and social networking in addition to peer support.⁴⁷⁵ When

⁴⁷² Maple Leaf. (February 2005) Canadian Forces Newsletter.

⁴⁷³ For example, Corring, D. (2002) Quality of life: Perspectives of people with mental illness and family members. *Psychiatric Rehabilitation Journal*, Vol. 25.

⁴⁷⁴ Campbell, J., and J. Leaver. (2003) Report from NTAC's National Experts meeting on emerging new practices in organized peer support. Available through: U.S. Department of Health and Human Services.

⁴⁷⁵ Nelson, G. (2004) What was learned about members of CSIs in Making a Difference. Available through: Centre for Addiction and Mental Health.

members joined these peer support groups, almost 40% were in unstable housing, one-third had been admitted to hospital in the past nine months and 25% reported the distress of psychiatric symptoms. After 18 months, they experienced fewer hospitalizations and fewer visits to emergency rooms than a control group of non-members. They had more stable housing, were experiencing fewer symptoms, and reported more friendships, all leading to an overall improvement in their quality of life. Qualitative data showed that members valued peer support as a safe place to recover and grow, protected from the negative judgments of society and the indifference of their communities.

Forchuk studied cost savings attributed to peer support.⁴⁷⁶ Using a randomized cluster design, she examined the experiences of 390 patients in 26 hospital wards in southwestern Ontario. She found that peer support, in combination with inpatient follow-up until a discharged patient was connected to community services, saved \$12 million in bed costs in one year. “Treating just one lonely person would pay for a part-time volunteer coordinator through reduced hospital and emergency costs.”

A study of Consumer/Survivor Initiatives, also in Ontario, found that with peer support, members used fewer mental health services (hospital days dropped from 48.36 to 4.29, and crisis service contacts went from 3.54 to 0.81). Members also increased their social and community supports.⁴⁷⁷

In light of these findings the Committee recommends:

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| 48 | <p>That research be undertaken to:</p> <ul style="list-style-type: none"> • quantify the benefits of self-help and peer support to participants, • identify savings to the health care system that result from peer support initiatives, and <p>That a portion of these savings be redirected to support further self-help and peer support initiatives.</p> |
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Further to research on outcomes, there has been substantial effort in Canada to conceptualize how consumer and family knowledge can shape thinking related to clinical treatment, community service, and government policy. In an important reworking of the Framework for Support document for the Canadian Mental Health Association,⁴⁷⁸ authors offer an idea called the Knowledge Resource Base which they argue is critical to the advancement of the understanding of mental health, mental illness and addiction. In

⁴⁷⁶ Forchuk, C. (2002) Therapeutic relationships: From hospital to community. Available at: Canadian Health Services Research Foundation, www.chrsf.ca.

⁴⁷⁷ Trainor, J., et al. (1997) Beyond the service paradigm: The impact of consumer/survivor initiatives. *Psychiatric Rehabilitation Journal*, Vol. 21, 132-140.

⁴⁷⁸ Trainor, J., E. Pomeroy, and B. Pape. (2004) *A framework for support*. Third edition. Toronto: Canadian Mental Health Association, National Office.

addition to traditional sources of knowledge that include evidence derived from social science (such as the outcome studies referred to above) and medical/clinical knowledge (studies of brain function, for example), the Knowledge Resource Base also includes experiential knowledge (the day-to-day lived understanding of illness as offered by persons living with mental illness, and their families) and the wisdom that comes from custom, tradition and history (honouring diversity and including other ways of healing).

I believe that peer support should be promoted and funded for people who have a personal experience with mental illness. Only individuals who have a mental illness truly understand what it is like to live with a mental illness. Because of that, we have a tremendous ability to help one another that the professionals just cannot match.

Families also need peer support so they can support one another and help navigate the system and advocate for their loved ones.

We would be more able to help one another if we had financial resources as so many people are also living in poverty or with very limited incomes. Transportation, communications by phone or internet is often not available to the individuals, themselves. —Anonymous

10.4.1 Summary

Research focused on self-help and peer support is relatively new, but the findings are promising. The theories that underpin the few studies that have been done and the methodologies employed are expanding the research horizon in new and innovative ways.

Research focused on self-help and peer support is relatively new, but the findings are promising.

Importantly, people living with mental illness, and their families, are participating in the formulation of questions as well as in data collection and analysis and the dissemination of findings. Such knowledge transfer practices are taking mental health and addiction in evolving and promising directions.

Conceptual work, such as that evidenced by the new edition of Framework for Support, provides a rich discourse that is inclusive of consumer and family participation and establishes the value of their role in the creation of new knowledge.

Therefore, the Committee recommends:

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| 49 | That the Canadian Institutes of Health Research (CIHR) support research into self-help and peer support, and that in determining which research projects to fund the CIHR utilize a review process that welcomes and understands the types of participatory methodologies that persons living with mental illness, and their families, prefer and find effective. |
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10.5 NEW VOICES

Self-help and peer support, while a welcome addition to the array of treatment and community services, challenges traditional thought in a variety of ways. People living with mental illness have their own perspectives regarding the causes and treatment of mental illness and addiction. Families speak out about lack of access to services, their exclusion from the treatment of their loved ones, and the failure of governments to enact laws that permit involuntary treatment.⁴⁷⁹

10.5.1 Service Delivery

Forty-one percent of respondents participating in the Committee's e-consultation stated that their experience with service providers was negative.⁴⁸⁰ Twenty-three percent described lack of respect as their worst experience, while others said misdiagnosis and inappropriate treatment (22%), delay in treatment (20%), physical violence (16%), denial of treatment (14%) and forced hospitalization (10%) constituted the worst. In the second phase of the e-consultation, persons living with mental illness, and their families, also distinguished between availability of services (hard to find) and their accessibility (the services are there, but there are too many barriers to getting access to them).⁴⁸¹

Forty-one percent of respondents participating in the Committee's e-consultation stated that their experience with service providers was negative.

People living with mental illness, and their families, also reported to the Committee that they felt themselves to be objects to be "handled" rather than human beings sharing relationships with their health care professionals.

While acknowledging the contributions of professionals, persons living with mental illness say that they are often not listened to or treated as whole people. Their lives become a series of unconnected problems to be managed only in ways that fit the various professional specialties. People living with mental illness, and their families, also reported to the Committee that they felt themselves to be objects to be "handled" rather than human beings sharing relationships with their health care professionals.

The safety of self-help groups has allowed people to speak out and to publish their views. Their personal experiences add power to these narratives. As a result, professionals, policy makers, administrators and the public are being challenged to alter their traditional views about people with mental illness and addiction and the way services intended to meet their needs are structured and delivered.

Back home I can remember my own personal experience wanting to start a self-help centre and, I should note, wanting to do it in French. There was a lot of

⁴⁷⁹ See also Chapter 4, Section 4.3.3, for a related discussion of the power of Review Boards to order treatment.

⁴⁸⁰ Chodos, H., N. Pogue and T. Riordan. (2005) E-consultation on mental health, mental illness and addiction: Phase one. Parliamentary Information and Research Service, Library of Parliament.

⁴⁸¹ Ascentum. (June 2005) Final report on the online consultation by the Standing Senate Committee on Social Affairs, Science and Technology.

opposition to that because they said, “There will not be any professionals around. Can you really do that by yourself?”

But we were deaf, we were stubborn, we never listened, and 18 years later I am here right now, and today that concept is accepted. Thus in that sense things have improved in that we have finally come to terms with the fact that mental health clients can do things by themselves, and for themselves, and they can have their own initiatives. —Eugene LeBlanc⁴⁸²

10.5.2 Recovery

Rather than using the language of diagnosis, symptoms, funding patterns, service utilization and economic burden, those living with mental illness speak of hope, recovery, connection, story-telling, healing journeys, loving attention, dignity, friends, spirituality, empowerment and the transformative power of crisis.⁴⁸³ These are sophisticated ideas that are not easily measured and managed; they do not fit comfortably in a system that prefers standardized procedures, uniform measures of accountability and homogeneous evidence-based best practices.

Rather than using the language of diagnosis, symptoms, funding patterns, service utilization and economic burden, those living with mental illness speak of hope, recovery, connection, story-telling, healing journeys, loving attention, dignity, friends, spirituality, empowerment and the transformative power of crisis.

Families, while more supportive of psychiatry and medication than are those undergoing treatment, also advocate for services that lie outside the medical circle of care.

Families, while more supportive of psychiatry and medication than are those undergoing treatment, also advocate for services that lie outside the medical circle of care — for example, affordable housing, income support and work.

The focus is on wellness and not illness, on ability not disability, on becoming at ease with one’s limitations and not remaining diseased within one’s limitations, on focusing on the beginning of the recovery process and not on remaining stagnant within one’s misery. —Joan Edwards-Karmazyn⁴⁸⁴

Despite their increasingly prominent role, people living with mental illness, and their families, do not feel generally that they are being heard; and there is evidence that this is so.⁴⁸⁵ While it is true that recovery, as a defining construct, has appeared in mental health

⁴⁸² 11 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eve-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁸³ Mead, S. (2003) Defining peer support. Available at: www.mentahealthpeers.com.

⁴⁸⁴ 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁸⁵ Canadian Mental Health Association, Ontario, the Centre for Addiction and Mental Health, the Ontario Federation of Community Mental Health and Addiction Programs and the Ontario Peer Development Initiative. (March 2005) Consumer/survivor initiatives: Impact, outcomes and effectiveness. Available at: www.ofcmhap.on.ca.

literature (it has had a much longer history in the addiction field), its revolutionary potential is not well understood, nor has it been widely acted upon.

10.5.3 Summary

New voices and views are often not taken seriously because those who advance them may be expressing somewhat diverging points of view. They may not agree with one another and the language they use may not be typical of the mainstream. However, with respect to people and families affected by mental illness and addiction, these disparate voices offer the opportunity for a richer, more nuanced dialogue among all stakeholders. They also provide a route to improved measures of accountability.

The “customers” of the Canadian mental health and addiction system say that they cannot find services when they need them and that, when they are lucky enough to find help, they are often unhappy with the services they do receive.

This valuable information must serve to improve the targeting of future government investment and the oversight of outcomes.

The “customers” of the Canadian mental health and addiction system say that they cannot find services when they need them and that, when they are lucky enough to find help, they are often unhappy with the services they do receive. These criticisms are not vague or insubstantial. They point exactly to what is wrong. This valuable information must serve to improve the targeting of future government investment and the oversight of outcomes. Therefore, the Committee recommends:

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| 50 | That accountability measures for mental health and addiction services include not just process issues such as numbers of visits, hours of counselling or dollars spent, but also address outcomes, such as respect, preservation of dignity, as well as a focus on hope and recovery, since these figure amongst the things that persons living with mental illness, and their families, value most. |
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10.6 CONTRADICTIONS AND CHALLENGES

As self-help and peer support continue to grow and become more adept at competing for government and other funding, they are challenged to remain true to their roots while, at the same time, being buffeted with the complicated demands, strings and “administrivia” that accompany money.

10.6.1 Paid Work Versus Unpaid Volunteerism

Self-help and peer support are based on independence as a core value. This argues that one of the main reasons their members experience success and satisfaction is that such groups are free to provide help in their own creative ways without direction from the “outside,” whether from funders or anybody else. Nevertheless, having work to do is important and

highly valued. Therefore, having the opportunity for a paid career as a peer support worker or on the staff of a funded self-help or peer support program is a very worthwhile goal to be pursued.

I want to be clear that [peer support] opportunities cannot be token ones. They deserve to be paid positions and paid at a wage that is a life-worth-living-wage; not a living wage, a life-worth-living-wage [emphasis added]. —Becky McFarlane⁴⁸⁶

Once self-help and peer support work is recognized as a paid profession, the door opens on all sorts of possibilities that offer the potential for considerable benefit: credentialling of peer support through formal education, emergence of sub-specialties, formation of associations, and regulation through codes of ethics and disciplinary boards. The danger to be avoided is that such traditional “structures” might transform self-help and peer support into something different, removing from them the fundamental reason for their effectiveness — the participation of their members solely on the basis of their lived experiences.

Having the opportunity for a paid career as a peer support worker or on the staff of a funded self-help or peer support program is a very worthwhile goal to be pursued.

10.6.2 Funded (With Strings) Versus Unfunded (Poor But Free)

The accountability requirements that accompany funding by government and many granting bodies are onerous. Just completing applications is skilled, labour-intensive work. Mainstream organizations often employ staff specifically to satisfy their funders’ demands for reports. The burden of data collection increases steadily, and mainstream programs are required to keep extensive electronic and paper records describing their service activities in relation to expenditures, all the while complying with security measures and privacy legislation. Self-help and peer support groups, by their very nature, do not ask for private health information; some do not even ask participants for their names or addresses. Their tradition is an oral one and their most valued activity, storytelling, defies conversion into data elements.

Once self-help and peer support work is recognized as a paid profession, the door opens on all sorts of possibilities that offer the potential for considerable benefit.

Many prominent self-help and peer support groups are effective without external funding (AA being the prime example). But there are also numerous examples of self-help organizations that compete successfully for grant money, receive government funds and raise funds through soliciting private donations.

Lack of funding often contributes to the marginalization of self-help and peer support groups and ensures that, funded or unfunded, their voices are drowned out by the power of professional interests.

But most live perpetually on a shoe-string budget without the means to mount the initiatives needed by their members or to maintain a presence at important decision-making tables.

⁴⁸⁶ 15 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Many such groups have difficulty acquiring funding because they challenge the very system through which the money tends to flow. Some decide not to pursue government funding because of the pressures that may then be applied to change their ways of doing things. Whatever the reason, lack of funding often contributes to the marginalization of self-help and peer support groups and ensures that, funded or unfunded, their voices are drowned out by the power of professional interests.

All of those initiatives have one thing in common: They are undervalued, under-funded and, because they do not fall within the prevailing cultural framework of clinical and unionized services, they are not a priority for governments and are often seen as an afterthought. In many instances, tokenism is very much enshrined in the mental health system. —Eugene LeBlanc⁴⁸⁷

10.6.3 The Limits of Best Practice Research

Concepts such as best practice have not served self-help and peer support well. The approach to models — of programs, of practice, of logic, of evaluation — that is common among professionals, does not translate well to the informality of the self-help culture. On the one hand, this has meant that not enough research has been done on the merits of self-help and peer support. On the other, because much traditional research has tended to discount the voices of people with direct experience of mental illness, it has cut itself off from the key source of information required to be able to assess outcomes of mental health interventions.

People living with mental illness, and their families, like many marginalized groups, have legitimate grounds for being suspicious of many traditional research methods, and for looking with greater favour on non-traditional methodologies such as participatory action research or underutilized ones such as qualitative methods. With the increased incidence of government funding, however, some groups are grappling with defining best practices, hoping that by adopting the methods of the professional culture they will gain respect and compete more effectively for funding.

The value of self-help and support groups in recovery has been very well documented. [...]Financial support for promoting and funding this important area is much needed. The self-help movement is growing, but could do so at a much faster pace. —Susan Kilbridge-Roper⁴⁸⁸

10.6.4 Summary

There is no doubt that tension exists between the informality of self-help and peer support and the formality of professional research methods and literature. In response to questions such as,

⁴⁸⁷ 11 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eve-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁴⁸⁸ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

- can and should peer-run support programs be classified, evaluated and understood by the same measures that govern services provided in the traditional mental health system, and
- would standardization of services supplant the healing bond of peer-to-peer relationships rendering them units of time at billable hours.⁴⁸⁹

it is very likely that peer support programs may not be able to reach their full potential if they do not embrace certification and accountability mechanisms. Therefore, the Committee recommends:

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| 51 | <p>That accountability requirements that are established for self-help and peer support groups do not impose an overly onerous burden on these groups, and that measures be taken to ensure that these groups are able to meet these requirements.</p> <p>That consumer and family-led certification and accreditation processes for self-help and peer support programs be developed and funded to ensure quality, and to sustain the unique contribution of self-help and peer support initiatives.</p> |
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10.7 SUSTAIN AND PROTECT

While mainstream organizations assert that a lack of funds compromises their ability to be effective, marginalized groups often hear the opposite — that funding will spoil them. People living with mental illness, and their families, have fought their way onto the mental health and addiction stage, step by difficult step, making on the way valuable contributions to the ways in which we think and speak about mental illness and addiction. The ideal of recovery comes from their ranks, as does the transformative reorientation of mental health and addiction treatment, supports and services toward the goal of recovery.

Self-help and peer support groups point out that the solutions they offer to people and families suffering from mental illness and addiction are more cost-effective than professional help.

How do you live day and night with a mental illness? Does it not make sense to talk to people who are living day and night with a mental illness? It makes perfect sense to me. —Linda Bayers⁴⁹⁰

Indeed there are contradictions and disagreements among individuals and families affected by mental illness and addiction, but this is hardly unusual. It is also true that the skills and attributes necessary to recover from a mental illness or addiction — or, as a family member,

⁴⁸⁹ Campbell, J., and J. Leaver. (2003) Report from NTAC’s National Experts meeting on emerging new practices in organized peer support, pp. 31-32. Available from: U.S. Department of Health and Human Services.

⁴⁹⁰ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

to support yourself, a loved one, and to navigate the system — are not the same as those required to lead complicated non-profit organizations; but then again, health professional education does not encompass much in the way of administration or management expertise. Usually, at least in the health professions, such skills are learned on the job.

For decades, professional organizations have had substantial funding. They have built infrastructure (computers, software and trained financial and informatics staff) to meet their accountability requirements. Consumer and family self-help and peer support organizations must begin almost from scratch because of their history of no, or limited, funding.

Self-help and peer support groups (and the research that focuses on them) point out that the solutions they offer to people and families suffering from mental illness and addiction are more cost-effective than professional help.

The Committee believes that the rewards of investing in self-help and peer support outweigh the risk that their cultures may be altered in unpredictable or negative ways. The key is to balance financial support with independence and the capacity to meet the necessary accountability requirements.

This assertion can hardly be disputed, given that they are providing help for free or at minimal cost. There is a danger that if such groups are excused from conforming to standard accountability procedures because of their lack of infrastructure, self-help and peer support will simply become more deeply entrenched as poor cousins, outside the circles of real power where the important decisions are made.

In case these fears seem trivial, it should be noted that the Australian mental health strategy, praised internationally for its focus on the involvement of consumers and their families and its values of hope and recovery, has encountered serious difficulties in sustaining its implementation. For example, funding for the National Resource Centre for Consumer Participation, despite excellent capacity-building work, was withdrawn in September 2004; it no longer exists.

The Committee believes that the rewards of investing in self-help and peer support outweigh the risk that their cultures may be altered in unpredictable or negative ways. The key is to balance financial support with independence and the capacity to meet the necessary accountability requirements.

The rise of the self-help movement in mental health and addiction heralds a significant change in the traditional power relations in our systems of care. With sufficient and regular funding, combined with ongoing government commitment and protection, its full benefits will be realized.

I believe that self-help initiatives such as consumer/survivor projects and many other self-help resources for mental health and addictions need to be formally recognized and acknowledged to be very effective and less threatening recovery solutions. As a result they require funding which is appropriate — and not shamefully lacking — for the excellent work that they do. —Anonymous

Therefore, the Committee recommends:

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| 52 | <p>That existing and new consumer and family organizations be funded at an annualized, sustainable level.</p> <p>That broad-based coalitions be funded and built among self-help and peer support organizations so that they do not continue to exist in isolation but are able to form networks with one another.</p> |
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10.8 CONCLUSION

The informed perspective of persons living with mental illness, as well as that of their family, is invaluable. Their organizations must be supported through stable, adequate, annualized funding. They must also be included in public education, research and knowledge transfer activities and thereby support the growth and development of the structures and skills that enable all organizations providing services to people and families affected by mental illness and addiction to operate effectively.



PART IV

**Research and Information
Technology**

11.1 INTRODUCTION

Good information is a prerequisite to good decisions... This is particularly true in the case of mental disorders, which until recently have been largely overlooked as public health issues. — World Health Organization⁴⁹¹

Research is fundamental to developing the quality information needed for the effective planning and delivery of the whole spectrum of mental health services. Research is necessary to:

- increase the recognition and understanding of mental illness,
- demonstrate how prevention of mental illness can be best achieved,
- provide the foundation for strategies for early intervention in mental illness to reduce the severity of illness and lead to faster recovery,
- develop more effective treatments, and
- lead to better and more cost-effective interventions through the use of technology.

In recent years, considerable progress has been made in all of these areas. Research done in Canada over the years has contributed significantly, both nationally and internationally, not only to expanding knowledge about how the brain functions, but also to developing new drugs and to the better therapeutic management of mental disorders. This has helped to greatly expand the treatment options that are available to people living with mental illness.

Consequently, it is of utmost importance that Canada devote the resources needed for effective research, disseminate the results of research, translate those results into clinical practice, develop a national research agenda, and collect the data necessary to track mental health in Canada. People living with mental illness are particularly vulnerable and should be treated with special care when they are the subjects of research. This chapter will address each of these issues in turn.

⁴⁹¹ World Health Organization, Mental Health Global Action Programme, 2002, p. 14.

11.2 SOURCES OF FUNDING FOR MENTAL HEALTH RESEARCH IN CANADA

11.2.1 The Fundamental Role of the Canadian Institutes of Health Research

Most research in mental health and addictions in Canada is led by researchers in universities and teaching hospitals, although increasingly it is done in collaboration with colleagues from outside academe. The federal government, through the Canadian Institutes of Health Research (CIHR), is the major sponsor of this research. CIHR was created in 2000 from the previous Medical Research Council as part of the federal government's commitment to making Canada one of the top five research nations in the world.

Population health research and health services research remain relatively weak in the areas of mental health, mental illness and addiction.

CIHR has divided the full range of health research into 13 sectors, each represented by an Institute. These Institutes are strategic networks that span disciplinary and geographic boundaries. One of them, the Institute of Neurosciences, Mental Health and Addiction (INMHA), has become the focal point for research into mental health, mental illness and addiction in Canada. INMHA has a very broad mandate: supporting research on the brain, the mind, the spinal cord, the sensory and motor systems, as well as mental health, mental illness and all forms of addiction. INMHA also works with federal and provincial departments and agencies and with non-governmental organizations to develop and implement strategies for research and the training of researchers.

As with CIHR-funded health research in general, research in mental health, mental illness and addiction encompasses the full spectrum of studies ranging from biomedical, to clinical, to health services, and to

There is still much to be learned in Canada about best practices in providing care and support to individuals with mental illness and addiction, whether in inpatient care, outpatient care, crisis response, housing, employment or self-help.

population health research. Most witnesses welcomed the inclusion of population health research and health services research in CIHR's mandate, areas of enquiry that had been excluded from the Medical Research Council's focus on biomedical research.

Population health research and health services research remain relatively weak in the areas of mental health, mental illness and addiction. Dr. Shitij Kapur and Dr. Franco Vaccarino, of the Centre for Addiction and Mental Health, told the Committee of the importance of redressing this situation given the effects of the broader determinants of health on mental illness and addiction.⁴⁹²

With respect to health services research, a literature review prepared for Health Canada in 1997 suggested that there is still much to be learned in Canada about best practices in providing care and support to individuals with mental illness and addiction, whether in inpatient care, outpatient care, crisis response, housing, employment or self-help. Even for

⁴⁹² Kapur, S., and F. Vaccarino. (2004) *Translating Discoveries into Care — Enhancing Research in Mental Illness and Addictions*. Paper commissioned by the Committee, p. 5.

those interventions where there is the strongest evidence relating to their effectiveness, there remains a pressing need for more detailed information about what works for whom.⁴⁹³

A paper from the World Health Organization backs this finding up, suggesting that there are many gaps in mental health research.⁴⁹⁴ According to the WHO,

- there have been few long-term follow-up effectiveness studies,
- research into the link between a population's mental health and public social and economic policies is lacking,
- the evidence base for some mental health strategies and programs is limited, and
- data on the relative costs and benefits of mental health interventions are sparse.

Dr. Rémi Quirion, INMHA's Scientific Director, told the Committee,

*There is still a dearth of specific information in this country, regarding incidence, prevalence, treatments, treatment quality, and knowledge transfer.*⁴⁹⁵

More in-depth research is essential to generate the results necessary to guide decisions about who should receive treatment and where, what treatment interventions should be provided, and how to provide assurance that the care delivered is appropriate to the particular needs of those living with mental illness and/or addiction.

Significant gaps remain in our understanding of mental health and addiction, gaps that can be filled only by much more research.

The Committee recognizes the federal government's role in creating CIHR and its decision to create INMHA, as well as the contributions of Dr. Rémi Quirion, INMHA's Scientific Director. Significant progress has been made in the promotion and conduct of research into mental health, mental illness and addiction. Nonetheless, the Committee shares INMHA's concern that significant gaps remain in our understanding of mental health and addiction, gaps that can be filled only by much more research.

Currently, INMHA is engaged in a priority-setting exercise, seeking input from stakeholders in the development of its second five-year plan. The Committee is encouraged by this process. The Committee would like to note that it recommends in Chapter 10 of this report that CIHR develop a funding stream focused on research into self-help and peer support, a relatively new and promising area of treatment and recovery.

⁴⁹³ Health Systems Research Unit, Clark Institute of Psychiatry. (1997) Best Practices in Mental Health Reform — Discussion Paper. Prepared for the Federal/Provincial/Territorial Advisory Network on Mental Health, Health Canada, pp. 27-28.

⁴⁹⁴ World Health Organization. (October 2004) WHO European Conference on Mental Health: Facing the Challenges and Building Solutions.

⁴⁹⁵ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

11.2.2 Federal Funding for Mental Health Research

CIHR is the largest public sponsor of research into mental health and addiction in Canada. In 2004-05, it allocated a total of \$53.7 million to research in mental health and addiction from its total budget of approximately \$700 million.⁴⁹⁶ CIHR spent a further \$98 million on research in the fundamental neurosciences, as well as all aspects of clinical, health services and population health research related to neurological diseases and disorders of the senses.

Approximately 60% of these funds were allocated through INMHA; the rest were allocated through other institutes such as the Institutes of Aboriginal People's Health, Gender and Health, Health Services and Policy Research, Population and Public Health, and Genetics. As with all of CIHR's resources, these funds were allocated in response to applications that were funded on the basis of scientific merit as assessed by CIHR's international peer review process. Approximately 30% of these funds were allocated as a result of CIHR's strategic initiatives.⁴⁹⁷

In addition to CIHR, two other sources of federal funding for research into mental health are the Social Sciences and Humanities Research Council (SSHRC) and the Natural Sciences and Engineering Research Council (NSERC). SSHRC supports research in the broad area of social psychology, and NSERC funds projects relating to fundamental psychological processes, their underlying neural mechanisms, their development within individuals and their evolutionary and ecological context. Neither SSHRC nor NSERC provide significant funds for mental health research. Together they contributed approximately \$6 million to mental health research in 2002-2003.⁴⁹⁸

Other federal sources of funds for research into mental health and addiction may include Statistics Canada, Canada's Drug Strategy (which funds the Canadian Centre on Substance Abuse), Health Canada, Correctional Service Canada (Addictions Research Centre), and the Canadian Health Services Research Foundation. The Committee did not receive information on the levels of funding provided by these sources.

We will return below to the issue of whether or not the level of funding from the federal government is adequate after reviewing the availability of funding for mental health research from other sources.

11.2.3 Other Sources of Funding for Mental Health Research

Pharmaceutical discoveries are an important product of research into mental illness, because drugs are an essential component of the treatment options for people living with mental

⁴⁹⁶ According to the CIHR's 2005-2006 Report on Plans and Priorities, its overall planned spending for 2005-2006 will be \$811.7 million. However, CIHR officials told the Committee that this includes flow-through monies for the Canada Research Chairs and Networks of Centres of Excellence programs.

⁴⁹⁷ Quirion, R. (21 June 2005) Testimony before the Standing Senate Committee on Social Affairs, Science and Technology. See also: Canadian Institutes of Health Research. 2005-2006 Report on Plans and Priorities.

⁴⁹⁸ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1- Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 10, p. 221.

illness. In fact, the pharmaceutical industry is the largest single source of funding for health research in Canada. In 2004, it invested \$1.6 billion in health research and development, approximately 27% of the total spent on health research in the country.⁴⁹⁹ Just how much of that funding of research by the pharmaceutical industry in Canada goes into mental health and addiction is not known, but it is thought to be substantial. Because of the strong presence of private industry in this area, the federal government is not a major sponsor of research into pharmaceutical therapies for mental illness. However, recognizing the importance of providing assistance to researchers to turn discoveries into practice, CIHR does provide funding for commercialization activities.

In most provinces, governmental bodies provide funds to support mental health and addiction research (e.g., Fonds de la recherche en Santé du Québec, Ontario Mental Health Foundation, Manitoba Health Research Council, Centre for Addiction and Mental Health (Toronto), etc.). These organizations provide approximately \$10 million per year, an important contribution to mental health and addiction research, but well short of the funding from the Canadian Institutes of Health Research.

In addition, many voluntary health organizations (VHOs), such as charities and foundations, can effectively respond to the support needs of different groups of people living with mental illness or addiction. Rarely, however, are such VHOs able to attract sufficient funds to sponsor research in the specific disorders on which they focus.

The pharmaceutical industry is the largest single source of funding for health research in Canada. Just how much of that funding of research by the pharmaceutical industry in Canada goes into mental health and addiction is not known, but it is thought to be substantial.

Moreover, there are only two national non-profit organizations whose mandates focus specifically on raising money to fund mental health and addiction research: the Canadian Psychiatric Research Foundation (approximately \$1.1 million per year) and NeuroScience Canada (\$160,000 to mental health and addiction research in 2004).⁵⁰⁰

Other VHOs collect funds almost exclusively for patient support and treatment. One of these, the Schizophrenia Society of Canada, has funded a total of 11 research fellows since 1994 using the proceeds of the \$1.5-million capital endowment fund initiated by the late Dr. Michael Smith's donation of half of his 1993 Nobel Prize award.⁵⁰¹

The stigma associated with mental illness and addiction creates significant barriers to its attracting appropriate publicity, getting corporate sponsorship, and raising funds for the support of research. This experience contrasts with that of other disease groups.

The Canadian Psychiatric Research Foundation (CPRF) told the Committee that the stigma associated with mental illness and addiction creates significant barriers to its attracting

⁴⁹⁹ Statistics Canada. (July 2005) Estimates of Total Spending on Research and Development in the Health Field in Canada, 1988 to 2004. Science Statistics, Service Bulletin, Cat. No. 88-001-XIE, Vol. 29, No. 5.

⁵⁰⁰ This information was obtained from the organizations' Web sites: www.cprf.ca and www.neurosciencecanada.ca.

⁵⁰¹ See the Schizophrenia Society of Canada Web site: www.schizophrenia.ca.

appropriate publicity, getting corporate sponsorship, and raising funds for the support of research. This experience contrasts with that of other disease groups such as cancer and cardiovascular disease, for which the respective health charities are strong and successful fundraisers and supporters of research:

*CPRF faces a difficult challenge in raising awareness and research funds to determine the causes, treatments and ultimate cures for a variety of mental illnesses. Tragically, the stigma of mental illness persists and as a result, millions suffer unimaginable despair in silence, fearful of adverse personal consequences that public acknowledgement of their illnesses might bring. Under these conditions, awareness remains low, understanding minimal, support mechanisms few, misconceptions rife and critical funding for research is critically low.*⁵⁰²

Given the difficulty faced by VHOs in raising funds, the Committee recommends:

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- 53 That the Canadian Mental Health Commission (see Chapter 16) work with non-governmental health organizations to develop and strengthen their fundraising capacities in order to raise more funds for research on mental health and addiction.**

The federal government could increase the value of the funds available by forming strategic partnerships with the private and non-profit sectors. Patrick McGrath, who holds the Canada Research Chair in Pediatric Pain, told the Committee,

*I think that the way to do it [get more money for mental health research] is to help CIHR partner, for example, with others to increase the pie. We do not have enough money in Canada in health research. We are still, even though it has improved dramatically, in the lower third of the G8 countries. It is not a matter of the CIHR having a lot of funding and they could just target that. Certainly targeted funding within CIHR is one good way, but I think it is more useful to collaborate with CIHR and try to grow the pie.*⁵⁰³

In fact, the main non-profit organization that funds research for mental health, the Canadian Psychiatric Research Foundation, told the Committee that it wants to have more partnerships with CIHR. The Committee believes that the same could be said of the private sector. While CIHR does engage in partnership activities, they could be increased. Therefore, the Committee recommends:

Voluntary organizations can also play an important advisory role in research into mental health, mental illness and addiction in Canada.

⁵⁰² Canadian Psychiatric Research Foundation. (June 2003) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 2.

⁵⁰³ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

54 **That the Canadian Institutes of Health Research actively seek out more opportunities for research partnerships on mental health and addiction with the private and not-for-profit sector.**

In addition to funding research, voluntary organizations can also play an important advisory role in research into mental health, mental illness and addiction in Canada. Dr. Quirion told the Committee that when INMHA was created, it sought out and fostered collaboration with 60 volunteer and non-governmental organizations. These groups participated in drafting the Institute's strategic plan and in the development of a strategy for increased funding.⁵⁰⁴

People living with mental illness, their family members, and representatives from VHOs told the Committee of their desire to participate in the research process. They are well placed to combat the pervasive lack of understanding and stigma associated with mental illness but feel disconnected from the research enterprise. For example, where appropriate, they could assist in the creation of research questions and their representatives could sit on review panels. This would allow researchers to better identify priorities and conduct research that is most needed by the mental health and addiction sectors. Importantly, their participation would reinforce the human aspects of science and be a continual reminder of the need for the practical application of research outcomes.⁵⁰⁵ The Committee therefore recommends:

55 **That the Canadian Institutes of Health Research formalize the involvement of non-governmental health organizations, persons living with mental illness and family members in the setting of mental health research priorities and participation in peer review panels.**

11.2.4 Targeted Funding Is Needed

(...) the funding of mental health and addictions research in Canada is currently inadequate. Mental health and addictions are under funded in an absolute and a relative sense. When one combines this systemic under funding, with the impact of stigma, the limitations of the NGOs fund-raising in this area as well as the lack of commercial incentives for a lot of these activities, the under funding becomes even more acute. Given that the other constraints cannot be easily overturned (stigma, limits to fund-raising in this area, lack of commercial incentives) — it is critical that the federal government show leadership in securing fair funding for mental health and addictions research.
—Dr. Shitij Kapur and Dr. Franco Vaccarino

⁵⁰⁴ 6 May 2003, http://www.parl.gc.ca/37/2/parlbus/commbus/senate/Com-e/soci-e/14eva-e.htm?Language=E&Parl=37&Ses=2&comm_id=47.

⁵⁰⁵ Gray, J., President, Schizophrenia Society of Canada. (12 May 2004) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 3.

The prevalence of mental illness and addiction in Canada is high and the economic burden enormous. A study on the global burden of disease estimates that mental illness accounts for 15.4% of the disease burden in established market economies, second only to cardiovascular disease (at 18%);⁵⁰⁶ nearly as many individuals battle depression as have cardiovascular disease. The total direct and indirect burden to the Canadian economy of mental illness was estimated to be \$14.4 billion in 1998.⁵⁰⁷

Many witnesses have argued reasonably that the huge burden of mental illness and addiction on society should be reflected directly in the funding dedicated to research into mental health, mental illness and addiction. Yet, several witness told the Committee that, applying this principle, the proportion of health research dollars allocated to mental health, mental illness and addiction is woefully inadequate. The Scientific Director of INMHA, Dr. Quirion, told the Committee,

The proportion of health research dollars allocated to mental health, mental illness and addiction is woefully inadequate. An adequate level of resources must be allocated to make progress.

*We agree that mental health research funding is insufficient in Canada, given the socioeconomic cost associated with these illnesses. . . . If we consider what we call the burden of disease, cost to society and incidence of mental illnesses, Canada, via the Canadian Institutes of Health Research, CIHR, needs to invest more in mental health research.*⁵⁰⁸

The Committee is of the opinion that research in these fields is of enormous importance and that it can lead to meaningful improvements in the lives of people living with mental illness and addiction in Canada. However, an adequate level of resources must be allocated to make progress. The Committee is very concerned that adequate resources are not being devoted specifically to research relevant to mental illness and addiction, especially given their social and economic burden on Canadian society.

The federal government, through CIHR, must accord research in mental illness and addiction higher priority than it currently enjoys.

To summarize, CIHR is the dominant source of funds that are available across Canada for research into mental health, mental illness and addictions. Funds from the private sector are primarily devoted to pharmaceutical innovations, and the provincial agencies are not well funded. Moreover, due to the stigma associated with mental illness and addiction, the ability of non-governmental organizations to raise money to fund research in mental illness and addiction is much less than in other major areas of health, such as heart and stroke, cancer, diabetes and arthritis. Hence, the Committee is of the strong opinion that the federal

⁵⁰⁶ Murray, C., and A. Lopez. (1996) *The Global Burden of Disease: A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020*. Harvard University Press.

⁵⁰⁷ Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1- Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 5, p. 101.

⁵⁰⁸ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

government, through CIHR, must accord research in mental illness and addiction higher priority than it currently enjoys.

The Committee is very supportive of the work done by CIHR as a whole and by INMHA specifically. While the Committee could ask CIHR to reallocate resources internally, this would mean taking away resources from other important health areas and potentially starving nascent research communities of necessary funds. Instead, the Committee is of the opinion that additional, incremental funds should be provided to CIHR for the purposes of funding increased research into mental health, mental illness and addiction.

INMHA has a very broad mandate and serves a large research community. The Committee is concerned that simply increasing the funds available to INMHA could result in more funds going to support research in fields such as the neurosciences, rather than to research into the much less well funded areas, such as the psychological and social factors associated with mental illness and addiction, where attention is sorely needed. Hence, the Committee believes that additional funds should be allocated in a dedicated fund, similar to the HIV/AIDS research funding that the federal government already provides to CIHR.

Also, as noted above, the clinical, population health research and health services research areas remain weak in the fields of mental health, mental illness and addiction. It is vital that efforts be made to close the significant gaps in our understanding in these areas, even if it must begin as far back in the research process as with the recruitment and training of first-class researchers. Another factor to keep in mind, as noted in the previous section of this report, is the importance of involving stakeholders in the decision-making process for research priorities. Therefore, the Committee recommends:

Incremental funds should be provided to CIHR for the purposes of funding increased research into mental health, mental illness and addiction. Additional funds should be allocated in a dedicated fund, similar to the HIV/AIDS research funding that the federal government already provides to CIHR.

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- 56 **That the Government of Canada commit \$25 million per year for research into the clinical, health services and population health aspects of mental health, mental illness and addiction.**
- That these funds be administered by the Canadian Institutes of Health Research (CIHR), through the Institute of Neurosciences, Mental Health and Addiction under the guidance of a multi-stakeholder board and in consultation with the Canadian Mental Health Commission (see Chapter 16).**
- That this \$25 million be incremental to the funding currently provided to the CIHR.**

The total CIHR budget will also affect the funds available for specific areas, including mental health and addiction. In its 2002 report on the state of the health care system in Canada, the

Committee called for an increase in the federal government's annual contribution to health research to 1% of the amount spent on health care.⁵⁰⁹ Meeting this target this year could involve almost doubling CIHR's budget to \$1.3 billion per year from the present level of \$700 million.

While the Committee is encouraged by the significant increases in federal funding allocated to CIHR early in its life, this support has essentially plateaued at 0.5% of total health expenditures in the last few years. The Committee reiterates its strong support for attaining the 1% goal, and recommends:

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| 57 | That the Government of Canada, within a reasonable time frame, increase its funding to health research to achieve the level of 1% of total health care spending. |
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A number of submissions to the Committee also stressed the importance of capacity, and some witnesses emphasized that insufficient numbers of physicians are participating in mental health and addiction research and that a major deficiency remains the fact that too few clinician scientists are being trained to carry out crucial clinical trials. Dr. Quirion told the committee,

*We hope to be able to convince the CIHR to set aside part of its budgetary envelope for training, and clinical research carried out by mental health and mental illness specialists.*⁵¹⁰

This means not just getting young researchers interested in mental health but also making sure that qualified and experienced clinical practitioners also have opportunities to do research. The Committee shares these concerns and believes that additional funds should be devoted for the recruitment, education and training of more researchers and clinician scientists in order to expand Canada's capacity to do first-class research in mental health and addiction. One of the priorities in INMHA's strategic plan for 2001-2005 is the creation of more training opportunities for clinician scientists. INMHA has already carried out a number of activities in this area, such as its BrainStar program. However, the Committee believes that more can and should be done. Therefore, the Committee recommends:

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| 58 | That the Canadian Institutes of Health Research, through the Institute of Neurosciences, Mental Health and Addiction, increase the funds available specifically for recruiting and training researchers and for clinical research on mental health, mental illness and addiction issues. |
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⁵⁰⁹ Standing Senate Committee on Social Affairs, Science and Technology. (October 2002) *The Health of Canadians — The Federal Role*, Vol. 6, Ch. 12.

⁵¹⁰ 21 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

11.3 DISSEMINATION OF RESEARCH FINDINGS

A major concern of researchers in mental health, mental illness and addiction is that there is currently no central database for all sources of funding. Neither is there an authoritative source of information on what is being investigated. The Canadian Psychiatric Research Foundation pointed out that there is no coordination among research funding bodies and no central responsibility for data collection. As a result, researchers find it difficult to negotiate their way through not only the government granting agencies, but also the private and the non-profit sector funding sources. The creation of a central database would not only help avoid duplication and overlap, it would facilitate communication among researchers. It would also help people living with mental illness, their families, and voluntary health organizations know what research was taking place.

Researchers may not be aware of research conducted in other areas of specialization which may affect their work, especially since mental illness and addiction issues cut across a wide diversity of disciplines. Provision of such information could encourage collaboration, enhance productivity and minimize the negative impact of competition among universities and hospitals. The Canadian Psychiatric Research Foundation recommended the establishment of a central database of research funding agencies that would encompass non-governmental sources of funding, a listing of what and where research is being conducted, and a site for maintaining a summary of research findings.⁵¹¹

Steps should be taken to: ensure that information about research funding opportunities is clearly communicated to researchers; facilitate interdisciplinary coordination and collaboration amongst the research community; and broadly distribute the findings of research to health care providers, people living with mental illness, and policy-makers.

The United Kingdom has undertaken an innovative approach to ensuring greater coordination amongst mental health researchers. In January 2003, the United Kingdom created the Mental Health Research Network, which is designed to provide infrastructure for mental health research.⁵¹² It acts as a central point of information and reference, connecting service users and care providers to researchers and mental health professionals. It hosts large-scale research projects in mental health that require multiple centres, and conducts much of the governance and financial administrative work on behalf of researchers. The Network currently involves seven research hubs which represent differing geographical and cultural bases. The hubs bring together academics, clinicians, and those involved in health and social care.

The Network was created because small, localized studies were often not conducive to allowing researchers to draw valid, general conclusions. Also, poor integration of resources, experience and expertise limited the ability of some mental health researchers to attract support from major funding bodies. This led to research that failed to inform public policy, and lacked coherence, relevance and credibility with users and professionals.

⁵¹¹ Canadian Psychiatric Research Foundation. (June 2003) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 6.

⁵¹² See the Web site of the Mental Health Research Network: <http://www.mhrn.info/>.

Setting up a similar network in Canada would take considerable time and effort and would have to be adapted to fit Canadian circumstances. Nonetheless, it should remain a long-term goal.

In the meantime, it may be possible to adopt certain elements. In particular, steps should be taken to: ensure that information about research funding opportunities is clearly communicated to researchers; facilitate interdisciplinary coordination and collaboration amongst the research community; and broadly distribute the findings of research to health care providers, people living with mental illness, and policy-makers.

The Institute of Neurosciences, Mental Health and Addiction does currently endeavour to assist information and knowledge exchange amongst researchers, but not in a systematic fashion. The Committee believes that the work of dissemination would be best performed by an organization that is able to bridge the various levels of government, non-governmental organizations and research institutions. The Committee therefore recommends:

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| 59 | <p>That the Knowledge Exchange Centre to be created by the Canadian Mental Health Commission (see Chapter 16) incorporate, amongst other things, an Internet-based database of research funding agencies and funding opportunities, identify what research is being conducted and where, and include summaries of research findings from all levels of government, universities, and non-governmental organizations.</p> <p>That the Knowledge Exchange Centre also assist in the exchange of information by organizing conferences, workshops, and training sessions on mental health research.</p> |
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11.4 KNOWLEDGE TRANSLATION

Knowledge translation is about turning the knowledge gained through research into more effective services and products and, for example, a stronger, more effective mental health system. It involves more than dissemination of information among researchers; knowledge translation involves connecting basic research to clinical practice. Dr. Ashok Malla, Head of Research, Douglas Hospital (Montréal), told the Committee:

Knowledge translation is about turning the knowledge gained through research into more effective services and products and, for example, a stronger, more effective mental health system.

The dissemination and application of discoveries remain major challenges that will be overcome only by greater investment.

*We need to define a clear pathway for transfer of knowledge with appropriate training. For example, we need to do studies in early intervention where we involve primary health care, teach them how to recognize mental illness early and then see if we can actually transfer that knowledge generally.*⁵¹³

And Ms. Downey, Executive Director, National Aboriginal Health Organization, pointed to the need for knowledge translation to be culturally appropriate:

*The relationship between knowledge translation and the need for culturally appropriate delivery of services and supports is recognized in many communities. We know that the mainstream approach to health care service delivery, while it addresses some of the needs, does not address all of them. Approaches that have been targeted towards Aboriginal communities over the last 25 to 30 years, we know are not working. We know that some of the health statistics are worse than they ever were. . . . Evidence-based community research on knowledge translation is necessary to determine the impact on quality of health services and products, and availability and use of cutting-edge research for community programming.*⁵¹⁴

Without effective knowledge translation, ineffective or even harmful treatments may continue, while effective, evidence-based treatments may not be adopted by policy-makers and mental health service providers.

The translation of a new idea or discovery into an accepted practice has three distinct phases. The first is the basic discovery that identifies, for example, a new genetic association, a new method of delivering care, a new way of engaging patients in therapy or a new idea for using an established treatment. The second phase is proof-of-principle, the clinical trial phase, which involves translating that discovery into care and demonstrating that it works in a controlled setting. The third phase, dissemination and application, involves incorporating the new practice into the pre-existing continuum of care and the community.⁵¹⁵

Eric Latimer, a health economist at the Douglas Hospital, told the Committee that mental illness and addiction research has had many successes at the discovery level, given the funding and number of researchers involved, but that the dissemination and application of discoveries remain major challenges that will be overcome only by greater investment.⁵¹⁶

Knowledge translation is an important part of CIHR's mandate. One of its objectives, as laid out in its founding legislation, is to excel "in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system, by promoting the dissemination of

⁵¹³ 16 February 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵¹⁴ 21 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵¹⁵ Kapur and Vaccarino (2004), p. 6.

⁵¹⁶ 6 May 2003, http://www.parl.gc.ca/37/2/parlbus/commbus/senate/Com-e/soci-e/14eva-e.htm?Language=E&Parl=37&Ses=2&comm_id=47.

knowledge and the application of health research to improve the health of Canadians.”⁵¹⁷ Knowledge translation is also one of CIHR’s three priorities, as outlined in its *2005-2006 Report on Plans and Priorities*.

One of the strategic priorities for INMHA is to promote linkage and exchange, through structured knowledge translation programs, between the research community and municipal, provincial and national levels of decision-makers as well as users of research results, including VHOs.

Witnesses agreed that this necessary, laudable goal could not be achieved at current levels of funding. During his testimony, Professor Tousignant, of the Centre de recherche et intervention sur le suicide et l’euthanasie, suggested that research budgets should contain funds dedicated to “scientific popularization.”⁵¹⁸ Many others told the Committee that knowledge translation is not done well in mental health and addiction research.

The Committee believes that knowledge translation is vitally important to ensure that people living with mental illness or addiction have access to the most effective treatments identified by research. Therefore, the Committee recommends:

Knowledge translation is vitally important to ensure that people living with mental illness or addiction have access to the most effective treatments identified by research.

60 **That the Canadian Institutes of Health Research (CIHR), through the Institute of Neurosciences, Mental Health and Addiction, substantially increase its efforts in knowledge translation in relation to mental health, mental illness and addiction research.**

That CIHR work closely with the proposed Knowledge Exchange Centre in order to facilitate knowledge exchange among decision-makers, providers and consumer groups.

11.5 A NATIONAL RESEARCH AGENDA

*Mental health and mental illness are critical and we should have a national type of agenda... — Rémi Quirion*⁵¹⁹

The Committee has found that in the area of mental health, mental illness and addiction there is no coherent policy or strategy in place to produce a coherent and coordinated response to the complex issues involved. Usually, mental disorders constitute

In the area of mental health, mental illness and addiction there is no coherent policy or strategy in place to produce a coherent and coordinated response to the complex issues involved.

⁵¹⁷ Canadian Institutes of Health Research Act, s. 4(h).

⁵¹⁸ 6 May 2003, http://www.parl.gc.ca/37/2/parlbus/commbus/senate/Com-e/soci-e/14eva-e.htm?Language=E&Parl=37&Ses=2&comm_id=47.

⁵¹⁹ 6 May 2003, http://www.parl.gc.ca/37/2/parlbus/commbus/senate/Com-e/soci-e/14eva-e.htm?Language=E&Parl=37&Ses=2&comm_id=47.

complex and chronic illnesses with a broad impact on society. Their determinants cut across many sectors, and their management involves many different health professionals.

Witnesses stressed the need for better coordination of efforts currently being undertaken by the federal and provincial governments, together with non-governmental organizations and the pharmaceutical industry, to deal with the many challenges posed by mental illness and addiction. In their paper for the Committee, Dr. Kapur and Dr. Vaccarino stated:

*(...) the issues of mental illness and addictions defy simple solutions. These illnesses have multiple determinants — biological, psychological and social, and adequate responses to them require coordination of multiple sectors. At present, research in these areas is a well-intentioned but uncoordinated effort. We strongly call for the development of a national policy or guiding framework to form the bases for a coordinated effort in the areas of Mental Health and Addictions Research.*⁵²⁰

Witnesses agreed on the need for a national research agenda.

Witnesses who addressed issues related to research in the mental health and addiction field agreed on the need for a national research agenda. In their view, such an agenda should build on current Canadian expertise, coordinate the currently fragmented research activities performed by a variety of bodies (governments, non-governmental organizations, pharmaceutical corporations) and ensure a balance among biomedical, clinical, health services and population health research applied to mental health, mental illness and addiction.

Greater coordination of research activities would benefit people living with mental illness or addiction. It is especially important that research is aligned with their needs.

Importantly, many witnesses stressed that now is the time to address the critical issues in mental health and addiction research. In particular, Dr. Quirion stated:

*The time is now. There is a great deal of expertise in Canada because of the national health care system. That allows us to collect data and to have data banks that are much more impressive than in the United States. Take the new genome research, for example. I think we could have a major impact and we should not be afraid to forge ahead. If we forge ahead with the expertise we currently have, we will succeed in finding the causes of brain diseases and of mental illnesses.*⁵²¹

The Committee believes that greater coordination of research activities would benefit people living with mental illness or addiction. It is especially important that research is aligned with their needs. Given CIHR's leadership role in funding health research in Canada, the Committee recommends:

⁵²⁰ Kapur and Vaccarino (2004), pp. 11-12.

⁵²¹ 6 May 2003, http://www.parl.gc.ca/37/2/parlbus/commbus/senate/Com-e/soci-e/14eva-e.htm?Language=E&Parl=37&Ses=2&comm_id=47.

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- 61 That the Canadian Institutes of Health Research, through the Institute of Neurosciences, Mental Health and Addiction, work closely with the Canadian Mental Health Commission (see Chapter 16), researchers, provincial and non-governmental research funding agencies, and organizations representing people living with mental illness or addictions in order to develop a national research agenda on mental health, illness and addiction.

11.6 SURVEILLANCE

Surveillance is necessary to find out the extent of the problem. Discussions the Autism Society Canada has had with the Canadian Institute of Health Information, Statistics Canada and Health Canada have been frustrating. There is acknowledgement that Health Canada has the mandate to deal with surveillance but there is not the political will to actually carry it out. I strongly urge the committee to press Health Canada to act according to their mandate and carry out surveillance for all mental health and brain-based disorders. It is a concern that the only activity on this front at the moment is a pilot project that will use data collections that already exist, rather than building a system that will allow the collection of the data that is needed. . . . We need the federal Department of Health to take responsibility for surveillance issues, which will facilitate better decision making. —Lisa Simmermon, Public Relations Director, Saskatchewan Families for Effective Autism Treatment⁵²²

Canada currently has no national picture of the status of mental health across the country. That is, we lack a national information base on the prevalence of mental illness and addiction in all their diverse forms. We also lack the information system required to measure the mental health status of Canadians and to evaluate policies, programs and services in the fields of mental health, mental illness and addiction. This is a major roadblock to determining the level of mental health services and addiction treatments needed by the provinces/territories and the country as a whole, and to evaluate the quantity and quality of services currently provided.

Canada currently has no national picture of the status of mental health across the country. Collecting quality data will provide better information for policy and decision makers inside and outside of government, as well as service providers and consumer groups.

Collecting quality data will provide better information for policy and decision makers inside and outside of government, as well as service providers and consumer groups. A surveillance system will provide measures that provinces could use to set targets on the way to reaching desired health goals and program outcomes.

⁵²² 3 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42454-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Two witnesses told the Committee about the importance of a surveillance system. Dr. Wade Junek of the IWK Health Centre emphasized the need to have better measurement and information systems:

If the fundamental goal is to improve the mental health status, or maintain even what we have, for our children and youth, one, we have to measure that status to determine if the actions are having an effect. We have to have outcomes and measures. Two, we have to incorporate information about those measurements into our decisions to allow for corrective action.⁵²³

Doug Crossman, Manager of Mental Health Services at the South Shore District Health Authority in Nova Scotia, told the Committee that it is important to have an outcome orientation.

We need better information systems and better population surveillance systems to monitor what we do and offer outcomes orientation. Frequently, we do not talk about outcomes. We talk about service utilization, which means the demand has grown on our service and so we need more money next year for more services. We should focus on what we are doing to improve the overall health of the population as opposed to expanding the service industry.⁵²⁴

Ongoing data on mental health and addiction issues are being collected by federal agencies. For example:

- The Canadian Institute for Health Information (CIHI) collects information on hospitalizations in acute care hospitals and psychiatric facilities.
- Statistics Canada collects information on mortality, including statistics on suicide.
- The National Population Health Survey includes questions on alcohol addiction, stress, social support, a distress scale, and a depression scale.
- The National Longitudinal Survey of Children and Youth includes questions on mental health and mental illnesses for a cohort of children across Canada.⁵²⁵

Canada does not currently collect data on an ongoing basis on the prevalence of mental illness and addiction among Aboriginal peoples, homeless people and the prison population — groups that are at higher risk for mental disorders than the general population. Also, hospitalization and mortality data exclude the majority of people living out-of-hospital and being treated for their mental illness or addiction.

⁵²³ 10 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵²⁴ 9 May 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵²⁵ Stewart, P. (2000) The Development of a Canadian Mental Illness and Mental Health Surveillance System: A Discussion Paper — Final Report. Prepared for the Canadian Alliance on Mental Illness and Mental Health.

While some of the data could serve as the foundation of a surveillance system, each of the relevant data sources has limitations. Another serious drawback is their narrow focus — they do not provide a comprehensive perspective on mental health and addiction in Canada.

In 2002, the Canadian Community Health Survey carried out by Statistics Canada provided, for the first time, prevalence rates for some mental illnesses, substance abuse disorders, suicidal ideation, and pathological gambling. However, Canada does not currently collect data on an ongoing basis on the prevalence of mental illness and addiction among Aboriginal peoples, homeless people and the prison population — groups that are at higher risk for mental disorders than the general population. Also, hospitalization and mortality data exclude the majority of people living out-of-hospital and being treated for their mental illness or addiction.

The Canadian Alliance on Mental Illness and Mental Health has been advocating the establishment of a national surveillance system that could be used in planning, implementing and evaluating policies, services and programs. The Public Health Agency of Canada has recently identified mental health and mental illness as a priority area and has decided to enhance the surveillance of mental illness through the development of a national mental illness surveillance program. It will spend \$400,000 over the next two years on a consultation process and on a select number of feasibility and demonstration projects. It aims to have a proposal for a national mental illness surveillance system by March 2007.⁵²⁶

The Canadian Alliance on Mental Illness and Mental Health aims to have a proposal for a national mental illness surveillance system by March 2007.

The Committee supports the initial actions taken by the Public Health Agency. However, a lot of work will need to be done to provide a complete picture of the state of mental health in Canada. The Committee is deeply concerned that the anticipated scope and pace of the proposed project may not be sufficient. Therefore, the Committee recommends:

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- 62 **That the Public Health Agency continue its efforts to develop in a timely way a comprehensive national mental illness surveillance system that incorporates appropriate privacy provisions.**
- That the Public Health Agency expand the range of data collected in cooperation with other agencies, such as the Canadian Institute for Health Information and Statistics Canada, as well as other levels of government and organizations that collect relevant data.**
- That, as it develops a comprehensive national mental health surveillance system, the Public Health Agency work with the Canadian Mental Health Commission (see Chapter 16).**

⁵²⁶ Mao, Y., Director, Public Health Agency. (2005) Presentation at the workshop on Expanding Mental Illness Surveillance in Canada, March 23-24.

11.7 RESEARCH ON HUMAN SUBJECTS

The Committee strongly supports research into mental illness and addiction because it can lay the foundation for future advances in treatment and prevention. However, research involving people poses many risks: abuse, misuse, exploitation, breaches of privacy, confidentiality, etc. Research involving human participants must be designed and performed in accordance with the highest scientific and ethical standards, and must protect the dignity of individuals and their families who make this valuable contribution to scientific progress.

The Committee acknowledges that individuals living with mental illness and addiction are particularly vulnerable research subjects. While all subjects of clinical research are vulnerable to some degree, the vulnerability of individuals participating in clinical mental illness/addiction research warrants particular attention. It is of paramount importance to protect the rights and well-being of these research participants and to promote ethically responsible research.

Research involving human participants must be designed and performed in accordance with the highest scientific and ethical standards, and must protect the dignity of individuals and their families who make this valuable contribution to scientific progress.

Research advances should not be pursued at the expense of human rights and human dignity. But nor should protections be so stringent so as to potentially exclude this vulnerable population from vitally important research that can improve scientific knowledge about their conditions and even benefit them as individuals.

In order to ensure the ethical conduct of research involving human subjects, institutions receiving research funding from the three federal granting agencies — the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC) — are required to adhere to the 1998 Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS). The TCPS specifies that research proposals should be reviewed by a Research Ethics Board which is charged with protecting the safety, privacy, and dignity of research subjects. Risks to the physical or mental well-being of participants are to be minimized; such risks must be balanced by benefits to the participants or society as a whole.⁵²⁷

An important part of the TCPS is that research involving humans may be undertaken only if the subjects give free and informed consent to their participation in the research.⁵²⁸ Given that most individuals with mental illness function reasonably well, they will be able freely and competently to give or withhold their consent for participation in research. In some circumstances, however, the cognitive capacity of people living with mental illness can be impaired, adversely affecting their decision-making ability.

⁵²⁷ Medical Research Council of Canada, Natural Sciences and Engineering Research Council and Social Sciences and Humanities Research Council. (1998) Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, Article 1.

⁵²⁸ *Ibid.*, Article 2.

The TCPS emphasizes the importance of voluntary consent and has provisions for individuals who may not be legally competent to give consent. However, the mental capacity of people living with mental illness to make decisions can exist at different levels to varying degrees and can fluctuate over time. In law, there are no degrees of capacity or incapacity. In its brief to the Committee, the Canadian Catholic Bioethics Institute explained:

The legal system tends to distinguish sharply between those who are deemed “capable” of decision-making regarding their health care and those who are incapable. Many persons with an active mental illness, such as severe depression or schizophrenia, may not meet the legal criteria for being declared “incapable”, and yet they do have significant impairment of their ability to understand their condition, appreciate their options, make prudent decisions about their mental health care and follow through on these decisions.⁵²⁹

The capacity to give consent is an essential condition for research involving human subjects. But the clinical assessment of mental capacity of people living with mental illness or addiction is a highly complex matter, and applicable clinical tests to assess competence are controversial. Illness may affect the ability to properly comprehend and assess the risks and benefits of participation in the research, or the steps required to implement the research plan. Also, given their vulnerability, people living with mental illness may feel coerced into participating.

More study is required to develop better safeguards and special protections for the ethical treatment of people with mental illness and addiction as subjects in research.

The Committee understands that sometimes research into mental illness and addiction can be carried out only on people who have an illness that impairs their ability to give consent. However, the Committee is concerned that currently the guidance for research involving human subjects considers only the dichotomy of consent freely given or those who are not legally competent to give consent.

The unique circumstances and vulnerabilities attending mental illness and addiction merit close attention to the ethical design, review and conduct of research. One possibility is for people living with mental illness to have an advocate to assist them with the processes involved in research participation.

The Canadian Institutes of Health Research has undertaken studies into research ethics, including the secondary use of personal information in health research and the appropriate use of placebos in clinical trials.⁵³⁰ However, the Committee feels that more study is required to develop better safeguards and special protections for the ethical treatment of people with mental illness and addiction as subjects in research. The Interagency Advisory Panel on Research Ethics, composed of experts from the three federal granting bodies is responsible for overseeing the development and evolution of the TCPS. Consequently, the Committee recommends:

⁵²⁹ Canadian Catholic Bioethics Institute. (20 February 2004) Brief presented to the Standing Senate Committee on Social Affairs, Science and Technology, p. 5.

⁵³⁰ See the Canadian Institutes of Health Research Web site at: www.cihr-irsc.gc.ca.

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- 63 That the Interagency Advisory Panel on Research Ethics conduct a study involving broad consultations as to whether the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans provides adequate protections and sufficient guidance for research involving persons living with mental illness and addiction. The panel should also explore the possibility of using patient advocates for persons with mental illness participating in research.

CHAPTER 12: TELEMENTAL HEALTH IN CANADA

The concept of *telemental health* (telemedicine and telepsychiatry) was mentioned frequently during the Committee's hearings. The more general term telehealth refers to health care and other services offered through a variety of information and communication technologies (ICT). *Telemental health* refers to services for mental health care that are delivered at a distance through ICT.

Telemental health refers to services for mental health care that are delivered at a distance through information and communications technologies.

Telehealth is not limited to clinical care applications. It also encompasses the application of ICT to training and continuing education. Telehealth technology can be used for a variety of purposes including diagnosis, treatment, training, education and consultation.

The first includes electronic health records, databases and registries, all examples of "store-and-forward" applications involving data stored at one location being sent to another location for use. The second category is two-way interactive television (IATV), audio/visual communication between at least two sites.

The spectrum of applications can be classified into two main categories. The first includes electronic health records, databases and registries, all examples of "store-and-forward" applications involving data stored at one location being sent to another location for use. The second category is two-way interactive television (IATV), audio/visual communication between at least two sites. It is also known as communication in real-time, live feed or, more commonly, videoconferencing.

The Committee was advised that these technologies have considerable potential in the mental health field. Dr. Ted Callanan, President, Psychiatric Association of Newfoundland and Labrador, told the Committee that:

*Psychiatry, perhaps, can offer the greatest range of its services efficiently and adequately via distance technology versus any other medical specialty.*⁵³¹

12.1 CURRENT PROGRAMS

Nationally, Canada Health Infoway (CHI) was established as a strategic initiative of federal, provincial and territorial governments to provide leadership in the development of a capacity for nationwide health information management and to achieve better coordination of the wide and rapidly developing variety of health information and technology initiatives already under way across Canada. CHI's mission is to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis. It is building on existing initiatives and pursuing collaborative relationships with all the stakeholders involved with a view to achieving tangible benefits to all Canadians.

Infoway has 21 approved telehealth projects under way and has completed 14 others – a total of 35 projects with an estimated investment value of over \$6 million.

⁵³¹ 15 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

Electronic health records are CHI's highest priority at this time, with five of the six investment programs focused on this objective. The sixth program, telehealth, was added to CHI's mandate in 2003. Local, regional and provincial programs can now apply to CHI for funding of their telehealth initiatives. Information obtained by the Committee from CHI indicated that, at the time of writing, Infoway has 21 approved telehealth projects under way and has completed 14 others — a total of 35 projects with an estimated investment value of over \$6 million. Infoway sees them as the foundation for more investments in the future.⁵³²

The number of local and regional telehealth programs and pilot projects has increased considerably over the past decade. Nevertheless, a common theme voiced by witnesses was that more resources are required for telehealth programs to reach their full

More resources are required for telehealth programs to reach their full potential.

potential. Some observed that while such programs would be beneficial to the well-being of Canadians throughout the country, the approach taken to date has been too localized and telehealth initiatives generally have been under-funded, or have encountered too many regulatory or bureaucratic roadblocks to be truly helpful at the level of individual patients and providers.

Others, however, such as Dr. Martha Donnelly, Head, Division of Community Geriatrics, Vancouver General Hospital, indicated that some of these issues are being addressed:

*There have been funding barriers that are now beginning to be overcome. There are potential medical and legal concerns...There are problems setting up the ports. Telehealth is not without cost...However, I think these things can be overcome.*⁵³³

Indeed, an October 2004 Health Canada report entitled *Telemental Health in Canada: A Status Report* reinforces the testimony the Committee heard regarding the slow but sure progress being made to overcome some of these hurdles. According to the report, telemental health is one of the most frequently used of all telehealth services because the process of psychiatric diagnosis is not primarily a physical one but relies instead on verbal and non-verbal communication. In fact, the report indicates that “all provinces and territories have been experimenting with telemental health, and some have already embarked in program implementation.”⁵³⁴

Telemental health is one of the most frequently used of all telehealth services because the process of psychiatric diagnosis is not primarily a physical one but relies instead on verbal and non-verbal communication.

However, the status report also points to many of the same obstacles that witnesses brought to the Committee's attention, including the inadequacies of the current telecommunications infrastructure in this country and shortages and under-training in human resources. It notes that policies in areas such as health care delivery, reimbursement and licensure, designed for face-to-face care, will require modification if they are to be adapted to the requirements of long-distance care.

⁵³² Alvarez, R., President and CEO, CHI. (7 November 2005) Letter to the Standing Senate Committee on Social Affairs, Science and Technology.

⁵³³ 8 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵³⁴ Health Canada. (2004) *Telemental Health in Canada: A Status Report*, p. iii. Available on-line at www.hc-sc.gc.ca/hcs-sss/pubs/chealth-esante/2004-tele-mental/index_e.html.

The Health Canada report lays out seven “lessons learned” that must be considered in order for Canada to advance its telemental health agenda effectively.

1. Careful planning is critical to the success of telehealth/telemental health services.
2. Uptake is always gradual and a project can take several years to fulfill its potential.
3. Evaluation should be built into every telemental health care program/initiative, and be adequately funded.
4. Despite limited evidence on cost-effectiveness, there seems to be real economies of scale.
5. Telemental health has demonstrated benefits to clients and providers, but the former are more easily converted than providers.
6. Telemental health presents a way to address shortages of mental health professionals but these same shortages can constrain its growth.
7. A comprehensive, multi-faceted strategy for managing change is crucial to success.⁵³⁵

The benefits and challenges of telemental health are discussed in more detail below.

12.2 BENEFITS OF TELEMENTAL HEALTH

12.2.1 Access to Care

The benefit from the wider deployment of telemental health (and all telehealth services) most frequently cited is its capacity to increase access to mental and other health services in rural and remote communities. Most mental health specialists are located in and around urban centres; residents of rural and remote communities must travel to those centres for diagnosis and treatment, a phenomenon referred to by some witnesses as “Greyhound Therapy.” The considerable financial cost and expenditure of time and effort involved can discourage people from seeking the care they need. Telemental health, on the other hand, could allow people to be diagnosed and cared for in their communities. Rural health care providers would also gain access to psychiatrists and other providers of mental health services in urban centres and be able to consult with other specialists as well via ICT.

Telemental health could allow people to be diagnosed and cared for in their communities.

By providing “low-profile” services to users, telemental health offers the added benefit of helping to address issues that relate to the stigma associated with mental health care services. Many people are discouraged from seeking the help that they need out of fear that it might become known that they are consulting a mental health specialist. Access to telemental health through a trusted family physician or other primary health care provider would therefore allow some rural residents to obtain mental health care services they might otherwise have declined to seek.

Telemental health offers the added benefit of helping to address issues that relate to the stigma associated with mental health care services.

⁵³⁵ *Ibid.*, p. iv.

For example, in New Brunswick, the Region 2 Health Authority has connected telemental health terminals in small-town emergency rooms with the psychiatrists at the Saint. John Regional Hospital who are on call 24 hours a day. Not only has this improved access but it has also alleviated problems associated with stigma because patients no longer have to travel to receive care. Krisan Palmer, a registered nurse and coordinator of the region's telehealth initiatives, told the *Medical Post* that telemental health services have "really helped to establish patient confidentiality."⁵³⁶ This regional initiative is now being rolled out province-wide.

12.2.2 Improving Recruitment and Retention in Rural Communities

Telehealth also has the potential to help ease the shortage of health care professionals in rural and remote areas. The current concentration of psychiatrists and other specialists in urban areas is unlikely to change in the near future. The use of ICT, however, could act as an incentive to attract and retain health care professionals in rural and remote regions of Canada. Telemental health can both help to provide necessary clinical back-up and foster connections between health professionals in remote areas and their urban peers.

Telehealth also has the potential to help ease the shortage of health care professionals in rural and remote areas.

Rural areas remain unattractive to many physicians and specialists due to the professional isolation they face there. Many individual practitioners are averse to the reduced interaction with medical peers that is a fact of rural and remote practice settings, and the obligation to conduct their practice largely on their own. Telehealth can help to redress this situation by giving those practitioners access to other health care providers, including mental health professionals.

Using technology such as videoconferencing, physicians and specialists can improve their education and enhance their knowledge by consulting with one another and by participating in conferences.

Another concern for many practitioners is that rural areas provide fewer opportunities for continuing medical education. Practitioners have to travel significant distances to attend conferences or to access other educational supports. Telemental health helps address this need. In this regard, Sharon Steinhauer, a member of the Alberta Mental Health Board, noted that "family doctors...can [have] not only immediate access to a psychiatrist and to psych. services support...but they can have ongoing training in those areas through telemental health sessions."⁵³⁷ Using technology such as videoconferencing, physicians and specialists can improve their education and enhance their knowledge by consulting with one another and by participating in conferences.

⁵³⁶ Sylvain, M. (Nov. 15, 2005) Telemental health service reaches out to remote N.B. *Medical Post*, Vol. 41, Issue 49.

⁵³⁷ 9 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/21eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

12.2.3 Collaborative Care

As noted earlier in this report, many regional health authorities are encouraging the creation of multidisciplinary teams in health care delivery. Collaborative care models of mental health care delivery are also becoming more widespread.⁵³⁸ Telemental health facilitates the collaborative care model and cooperation between family physicians and psychiatrists.

Telehealth provides a means by which a collaborative model for mental health can be put into practice.

Although there are still barriers to be overcome (including the funding and remuneration issues described below), telehealth provides a means by which a collaborative model for mental health can be put into practice through video consultations, case conferences and educational sessions, Web-based training resources and continuing medical education programs.

Moreover, the Health Canada status report on telemental health points out that it is important to seek ways to integrate telemental health into the broader thrust of primary care reform, suggesting that:

...telemental health be developed and implemented not in isolation, but as an integral part of the continuum of care. In this way, telemental health would have the potential to act as a catalyst for reform, particularly primary health care reform, according to key informants from many jurisdictions.

12.2.4 Aboriginal Communities

That telemental health services have the potential to improve access to care in rural and remote areas is of particular importance for many First Nations and Inuit communities. Access to psychiatric services in most northern Aboriginal communities is limited; the majority currently have none, and in others it is woefully deficient.⁵³⁹ Often, communities share a single health care professional who travels between them or to whom clients must travel to obtain care. Mental health care professionals and other specialists are usually available only at great distances and the associated travel costs can be very high. Ian Potter, Assistant Deputy Minister, First Nations and Inuit Health Branch, Health Canada, told the Committee:

Once properly funded and implemented, telemental health could help to provide the level of service that is desperately needed in so many communities.

*One promising area ... is tele-mental health services, whereby we do not take people out of the community where they can actually communicate with others. Rather, we have them stay and talk to their relatives and provide them a link to psychiatric services in facilities elsewhere through a videoconferencing system.*⁵⁴⁰

Once properly funded and implemented, telemental health could help to provide the level of service that is desperately needed in so many communities.

⁵³⁸ See Chapter 5 for a more detailed discussion of collaborative care.

⁵³⁹ See Chapter 14 for a more detailed discussion of the enormous challenges facing Aboriginal communities in improving the mental well-being of their people.

⁵⁴⁰ 20 April 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

12.3 CHALLENGES

12.3.1 Jurisdictional Issues: Licensure and Reimbursement

One of the most attractive features of telemental health — its capacity to offer services over vast distances — also presents one of the major challenges. The practice of medicine is a provincial/territorial responsibility; practitioners are licensed within each province or territory. A key benefit of telehealth activities is that it allows collaboration between mental health professionals across jurisdictional boundaries. However, regulating and funding this practice requires licensing agreements among the various jurisdictions in which health professionals participating in telemental health, or telehealth generally, are licensed and located.

Most provinces have yet to address adequately the issues related to reimbursement policies specific to their jurisdictions.

While some jurisdictions have licensing agreements for cross-border practice, most do not. Licensing agreements between Prince Edward Island and Nova Scotia permit the sharing of some telepsychiatry services, but comparable agreements do not exist in most other parts of Canada. Their lack can make health care professionals hesitant to participate in telemental health initiatives.

Similarly, developing the right reimbursement policies represents another challenge that must be overcome if telehealth services are to be expanded. While licensing is the responsibility of the College of Physicians and Surgeons of each province or territory, the provincial and territorial governments must themselves address whether telemental health services are to be insured and paid for out of their publicly funded health plans.

Health Canada's status report asserts that most provinces have yet to address adequately the issues related to reimbursement policies specific to their jurisdictions:

Most jurisdictions now have policies to reimburse physicians for telehealth (including telemental health), but these are generally considered inadequate for attracting service providers to telemental health. For example, as indicated by the key informants, in Alberta, physicians receive the same fee for a telehealth session as for face-to-face care, when in reality a telehealth session takes longer, according to key informants. Saskatchewan's physician payment schedule does include payments to compensate physicians for delays caused by technical problems. In Newfoundland, child psychiatry is the only telemental health service for which there is any fee-for-service reimbursement. In Manitoba, the fee schedule omits case conferences. In Quebec, the legislation specifically provides that telehealth is not an insured service. In British Columbia and Ontario, there are no fee-for-service provisions for patient/provider consultation through videoconferencing. In order to recruit service providers, project and program managers have attempted to mitigate the impact of inadequate fee-for-service policies by using contract agreements, salaried physicians and session fees paid out of project/program budgets.⁵⁴¹

⁵⁴¹ Health Canada. (2004) Telemental Health in Canada: A Status Report, p. 11.

The Committee therefore recommends:

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| 64 | <p>That the provinces and territories work together to put in place licensing agreements and reimbursement policies that will allow for the development of telemental health initiatives across the country.</p> <p>That the Canadian Mental Health Commission (see Chapter 16) work with the provinces and territories to identify and resolve any outstanding licensing and reimbursement issues.</p> |
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12.3.2 Funding

Telemental health activities began as temporary or pilot projects and have evolved into funded long-term programs. While some have secured the funding required to maintain their current level of operations, in many there is insufficient funding to expand or to create new projects. Up-front costs for a telemental health site include videoconferencing equipment, which can cost as much as \$100,000 per system, while communication between sites requires additional funding for Internet, Integrated Services Delivery Network (ISDN) or satellite connection.

Although the federal government has provided financial assistance for the development of telemental health services, it does not implement or maintain these or other health services directly, with the notable exception of health services to those populations for which the federal government has responsibility (First Nations and Inuit, veterans, federal inmates, immigrants and refugees, military and the Royal Canadian Mounted Police). For this reason, telepsychiatry services are usually administered by provincial/territorial governments, academic institutions, regional health authorities or hospitals, or some combination thereof.

Funding and sustainability are a major issue for many programs, particularly in the North where telecommunication costs are very high due to a greater dependence on expensive satellite connections. The termination of a number of Health Canada initiatives has prevented the expansion of telemental health programs. Such now defunct initiatives related to telemental health include the Canada Health Infostructure Partnerships Program (CHIPP), Health Infostructure Support Program (HISP), Health Transition Fund (HTF), Knowledge Development and Exchange (KDE), and Applied Research Initiative. Many existing provincial/territorial programs that continue to operate were started under these programs.

As indicated above, Canada Health Infoway was created to help support, among other things, the development of telehealth programs. CHI funding, however, does not cover operating costs, networking infrastructure, or maintenance and enhancement of hardware, software systems and servers. Funding for such telemental health services comes largely from the provincial and territorial governments.

It is important for the federal government to assist with the deployment of telemental health initiatives across the country.

According to the previously mentioned Health Canada status report, all governments fund some telemental health services, but to significantly varying degrees. In some jurisdictions, uncertainty of

funding is a significant obstacle to expanding telemental health services. Ian Shortall, Division Manager, Bridges Program, Health Care Corporation of St. John's, told the Committee that "we need to use more technology, telepsychiatry... but have not been able to sustain the funding to carry that forward."⁵⁴²

The Committee believes that it is important for the federal government to assist with the deployment of telemental health initiatives across the country. In this respect, the Committee takes note of the announcement on 13 October 2005 that the Government of Canada has invested \$4.62 million to advance broadband technologies that will support improved health care and emergency preparedness in rural regions.⁵⁴³

Extending the same funding ratio to the telehealth program as the others have would help to accelerate investments and advance telehealth.

Over time, and once the infrastructure is in place, it should be possible for the provinces and territories to use the savings from reduced transportation and other costs that will be gained by implementing telemental health services to fund the operating costs of those services. Meanwhile, in order to assist with the transition towards this "steady state," the Committee recommends:

65 That telemental health initiatives be eligible for funding through the Mental Health Transition Fund (see Chapter 16).

In addition, Richard Alvarez, President and CEO of Canada Health Infoway, informed the Committee of a restriction in its funding agreement with the federal government concerning telehealth: CHI can cover only up to 50% of eligible costs of telehealth projects.⁵⁴⁴ This constraint does not apply to other CHI programs, in which the average funding ratio is now 75(Infoway):25(sponsor). The Committee agrees with Mr. Alvarez that extending the same funding ratio to the telehealth program as the others have would help to accelerate investments and advance telehealth in Canada. The Committee therefore recommends:

66 That the funding agreement between Canada Health Infoway and the Government of Canada be revised so that Canada Health Infoway is no longer limited to being able to cover only up to 50% of eligible costs of telehealth projects and is allowed to establish the same ratio for its investments in telehealth projects as it uses in other projects.

⁵⁴² 14 June 2005, http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47.

⁵⁴³ Industry Canada (13 October 2005). Press release available on-line at <http://www.ic.gc.ca/cmb/welcomeic.nsf/558d636590992942852564880052155b/85256a5d006b97208525709900672b4b!OpenDocument&Highlight=2,broadband>.

⁵⁴⁴ Alvarez, R., President and CEO, CHI. (7 November 2005) Letter to the Standing Senate Committee on Social Affairs, Science and Technology.

12.3.3 Evaluation

Before any health service can be adopted as standard practice, it must first be thoroughly evaluated. A significant barrier to the implementation of new telemental health programs is the absence of standard evaluation practices. Since there are no national standards by which to evaluate telemental health projects, studies that assess the effectiveness of such projects do not use common sets of indicators and cannot be reliably compared to each other. Without consistent and reliable evidence relating to telemental health as an effective method of care, health authorities and provincial/territorial health departments are understandably reluctant to fund new projects.

The Committee therefore recommends:

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| 67 | <p>That the Knowledge Exchange Centre (see Chapter 16) work with the provinces and territories, as well as with other bodies such as the Canadian Institute for Health Information, in order to measure the cost-effectiveness of telemental health care delivery compared to traditional mental health service delivery.</p> <p>That the Knowledge Exchange Centre assist in the development of evaluation tools for telemental health services.</p> |
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12.3.4 Human Resources

The shortage of mental health professionals in many areas across Canada severely limits the development and implementation of telemental health services. As noted previously, telemental health can have a positive impact on attracting and retaining health care providers in rural and remote locations. However, getting telemental health services up and running can be difficult, especially when there is heavy competition for the use of scarce human resources. As stated in Health Canada's status report: "Telemental health represents a way around shortages of mental health professionals, but these same shortages can constrain its growth."

The provision of mental health services via telecommunications seems a very promising option, but it is still new. Many mental health care providers remain unfamiliar with telemental health, sceptical about its utility and, indeed, uncertain about their capacity to use it effectively. While some providers are now actively striving to adapt their skill sets in order to deliver care through telehealth, others are proving resistant to the conversion.

The Committee therefore recommends:

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| 68 | That the Canadian Mental Health Commission (see Chapter 16) encourage the inclusion of telemental health instruction in medical schools, and that it work with the provinces and territories, as well as with the relevant professional bodies, to make information available on telemental health to current mental health providers through its Knowledge Exchange Centre. |
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