Home Care and Mental Health Web Discussion: Next Steps (Short Version) – April 2005

CANADIAN MENTAL HEALTH ASSOCIATION

ASSOCIATION CANADIENNE POUR LA SANTÉ MENTALE

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- Nadine Henningsen, Executive Director, Canadian Home Care Association
- Jean Hughes, Chair, Home Care Committee, CMHA National
- Bonnie Pape, Director, Programs and Research, CMHA National

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Jayne Whyte
Project Facilitator

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The views expressed herein do not necessarily represent the official policies of Health Canada.

Introduction

The Home Care and Mental Health web discussion "Next Steps" was designed to meet Health Canada's request for policy advice on home care and mental health. The Canadian Mental Health Association, National office organized a time-limited national electronic stakeholder forum during February and March 2005.

The purpose of the web discussion was to continue the policy dialogue on the following issues:

- access to home care by consumers with a mental illness[1];
- assessment of consumer needs for home based services;
- the role of informal/ family caregivers[2] and of consumers in service provision;
- cost-effectiveness of home care for consumers with a mental illness;
- accountability and outcome measures; and
- health human resources in home care for consumers with a mental illness.

Sponsor Information

The Canadian Mental Health Association (CMHA) is a national, voluntary association that has existed for over 80 years to promote the mental health of all people. Working through a national infrastructure of more than 125 local branches and regions and 12 provincial/ territorial divisions, we deal with policies and services for those with mental illness, and develop interventions to enhance the mental health of specific population groups as well as the general public.

The CMHA National Office has already engaged in important and relevant work in home care and mental health. Over the last five years, CMHA had conducted research that resulted in three documents: *Home Care and People with Psychiatric Disabilities*, *Supporting Seniors' Mental Health through Home Care: A Policy Guide* and *Supporting Seniors' Mental Health through Home Care: A Guide for Home Care Staff*[3]

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[1] The term "consumer" is used by the community mental health sector; the term "client" is used by the home care sector. For the purposes of this work, "consumer" and "client" may be used interchangeably.

[2] "Informal caregivers" are family and friends providing unpaid care to individuals. The Steering Committee of the Canadian Home Care Human Resource Sector study recognized that other terms, such as "family caregiver" may be used. This type of care can be provided by friends and neighbours, as well as family members. "Informal" and "family" are used interchangeably in this report.

[3] Links to these reports are on the CMHA National website http://www.cmha.ca/english/research/index.html

Background

In September 2004 CMHA completed a project for Voluntary Organizations in Collaborative Engagement (VOICE) in Health Policy exploring the interface between the home care and mental health sectors. That project resulted in a literature review, solicited position statements from stakeholders, and a two-day forum in June 2004 that brought stakeholders from both home care and mental health sectors together from across the country. Forum participants built on the position statements that clarified and summarized their own positions, determined key issues, and identified values and principles that must underpin federal policies in relation to home care services for people with mental illness and mental health problems.

While this forum made important strides in defining the problem and the foundational elements of policy, it was acknowledged by all participants to be just a beginning. First of all, some key stakeholders, such as the Canadian Home Care Association were not able to be present at the forum. Secondly, while there was consensus about key general principles, the time limitations of the forum and the project prevented the discussions from reaching a level where policy recommendations could be developed. Although some concrete recommendations were made, the forum was more successful in developing a set of principles and a vision on which to base policy advice.[4] And finally, the energy and synergy at the forum led to strong hopes and expectations that the fledgling home care/mental health network brought together by this project could continue work on its collective agenda related to policy development in mental health and home care.

The Web discussion follows up on the Voluntary Organizations in Collaborative Engagement (VOICE) project, "Home Care Sector and Mental Health" Case Study report and Final Report based on the national forum in Toronto in June 2004.[5]

The final VOICE project Advisory Group meeting recognized the need to continue the process of stakeholder consultation.

Methodology

To continue the consultation and policy building, CMHA conducted an electronic forum to allow stakeholders to exchange and discuss their comments. Comments were stored, collected, and thematically analysed to prepare this report which could be used as groundwork for follow-up to activities to solidify policy advice to the federal government.

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[4] See Appendix B section "Agreements from the Policy Forum" in the full document available at www.cmha.ca

[5] Full text of the Final Report and Case Study are available on the CMHA Ontario web site http://www.ontario.cmha.ca/content/reading_room/policydocuments.asp?cID=5397

A steering committee was established to provide guidance and assistance for the Home Care and Mental Health web discussion. The Project Steering Committee drew on CMHA's volunteer leadership in this area, as well as the working relationship with the Canadian Home Care Association. Other Steering Committee members came from the Canadian Caregivers Coalition and Health Canada. Jayne Whyte, a consumer advocate who had served on the Home Care Sector and Mental Health Project Advisory Group, was contracted as consultant facilitator for the Web discussion.

A decision was made to focus on five theme areas:

- Access
- Assessment
- Family/ Informal Caregivers
- Human Resources
- Accountability

Forum content was developed with input from all Steering Committee members. Background information on the project and introductions to each topic area were posted on the CMHA National web site with links to the web discussion pages. The web discussion ran for six weeks beginning February 15 and ending March 24, 2005.

A letter of invitation was sent to all participants with e-mail addresses compiled for the June forum, plus a number of other contacts suggested by steering committee members and the facilitator (n=150). Four reminder e-mails were also sent during the discussion to summarize discussion to date or to re-introduce key area topics. Invitation recipients were encouraged to forward the information about the web discussion to anyone who might be interested. Steering Committee members also took responsibility for distribution to their mailing list contacts in Health Canada, CMHA, the Canadian Home Care Association and the Caregivers Coalition of Canada.

Statistics

Twenty-one persons made one or more entries into the discussion. Participants came from BC, Alberta, Saskatchewan, Manitoba, Ontario, Quebec and Newfoundland. Four consumers, four from the informal family sector, eight from the formal system, two policy makers, one student and two educators self-identified in the discussion. One participant self-identified as consumer and as social worker.

A gender breakdown based on names and other personal information shows that of the twenty-one respondents, fifteen (15) were female, four (4) were male, and two (2) did not indicate gender. (Note: names used on web forums are often pseudonyms that do not necessarily reflect the gender of the participant.)

During the first week, consumers (C/S) responded, possibly because they noted the new discussion on the list with the well-established consumer forum on the CMHA National website. Subsequent invitations encouraged caregivers and policy makers to participate.

At the end of the discussion on Thursday, March 24, the Home Care and Mental Health web discussion has 70 postings under the eight headings on the Discussion Group list. The facilitator wrote seventeen (17 =24%) of the items to start discussions and respond to participants. It should be noted that the facilitator entered items, with permission from JH, FB and Carol, received by personal e-mail or fax.

About Web Discussions

The use of Internet and the World Wide Web as a tool for sharing information, and bringing people together for story telling, discussion, analysis of data, and decision making is in early stages of development and this experiment shows some of the limitations.

One of the disappointments was the small number of responses and the limited interaction among participants. Questions raised by the facilitator to probe and continue conversation, for the most part, went unanswered.

The reminder notices provoked some response, with the exception of week 5 when no postings were made to the site.

Unfortunately, there was no counter of "hits" for the Home Care and Web Discussion so there is no way of knowing how many people visited the site to read the materials but did not leave a message. We know of one person who signed in under "A Bit about You" but did not make any comments on any of the topics. As the facilitator checked e-mail after the site closed, JH had written a one line note, "the material on the site is quite interesting!"

Summary of Web Discussion

Someone suggested that web forums are like phone-in radio shows. You get the experience and opinions of the people who participate which may or may not provide a complete and balanced sample. This section pulls together the quotes from the web discussion under the themes of General Comments, Access, Assessment, Informal/ Family Caregivers, Human Resources, and Accountability.

The names of respondents will be used in this summary to recognize the different contributors. Some of the names are or could be pseudonyms. For persons who used their full names, initials are used in this summary to increase anonymity. Because the same person could enter ideas under more than one topic, personal identifications in this summary allow the reader to get a more complete picture of the situations and suggestions offered.

General Comments

Participants in the Home Care and Mental Health web discussion illustrate that offering Mental Health Home Care can be a complex and sensitive challenge.

A letter from A.L. (province undisclosed) offered a list of major difficulties she experienced in trying to introduce mental health home care. Her concerns touched on the problems of health care "infrastructure" including attitude, a lack of community psychiatry, and lack of training for professional caregivers. This affects access and debates about who might provide service based on primary and secondary diagnosis. Anne also identified stigma and lack of understanding about mental *illness* among professionals and the public.

Danica, a psychiatric nursing student in Vancouver was investigating a variety of ways to support persons with mental illness and dual diagnosis who are being released from an institution.

Carol, a Registered Nurse who is involved in nursing education in Saskatchewan, noted that SIAST assignment explores availability of mental health services in communities and reasons why they are lacking.

A community service worker in a First Nations service in Manitoba said that there are some programs available, through the Regional Health Authorities, the local CMHA branch, Adult Foster Care and the proctor program. She suggested they could be built upon to develop a comprehensive mental health home care program, both on and off reserve.

Cheylou suggested a program PACE / Recovery Curriculum available through the National Empowerment Centre.[6] PACE (Personal Assistance in Community Existence) focuses on recovery, reducing and coping with mental illness to allow a person to live a full and satisfying life.

Access

'Immovable object' expressed the discouragement that results when appropriate help is not available, especially when there are both physical and mental health needs.

Lady Guinevere spoke of her experience as a person who receives home care because she has MS and the difficulties of physical disability compounded by depression, and the importance of offering resources people need to have a satisfying life.

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[6] The link to this site is www.power2u.org/index.html This program was one of the resources for the CMHA document *Recovery Rediscovered: Implications for Mental Health Policy in Canada –July 2003* at http://www.cmha.ca/english/research/index.html

Cheylou has been our most frequent contributor with nine submissions in her role as an advocate. She points out that people with mental illness and their families both need assistance in dealing with crisis and long-term care.

She also notes the needs for a complete range of support including housing and appropriate, comprehensive mental health services. She, and others, expressed concern that medication alone is not enough when there are financial, medical, transportation, and security concerns. After hospitalization, the problems of where and how to live still need to be addressed. P.L. from northern Alberta felt he received better support for his alcohol problem than people who have mental illness.

Cheylou also made suggestions for supervision and emotional supports for the medication and symptoms of mental illness, and social supports including supportive housing, friendships, employment, and community involvement that would help people with long term and severe mental illness. She recommended flexibility to deal with rare and difficult cases and asks questions who makes referrals and decides what works and doesn't work for particular situations.

"Retired' questioned the feasibility of some of the ideas for interventions, socialization and employment especially when suitable resources are not available.

Cheylou raised another area of concern, the older adult who remains at home when it is no longer safe. Another respondent who self-identified as RPN also expressed concern for the seniors who have various needs including mental health services in either rural or urban settings.

D.S. added her thoughts as a visiting nurse on the need for appropriate access and assessment for people with mental health needs. She also points out that community care involves the need for appropriate referrals and the gaps in services.

Debbie's new career as an educator has added youth and young parents as a population that could benefit from access to mental health home care.

Cheylou's recommendation that home care workers be aware of the complicating factors of addictions was shared by a case manager, George. This led to a response worrying that lack of privacy would prevent asking for help.

Privacy and respectful support was also raised as an issue for persons who are gay, lesbian, bisexual and transgender, transsexual and who may be older, physically or mentally challenged, of colour and /or other minorities. Dick suggested that home care providers get training by from the minority populations to provide sensitive care to these particularly vulnerable populations.

Lady Guinevere who described herself as living with MS and depression responded that home care givers need to be trained in areas of compassion, sensitivity, and "caregiving" beyond the doing-of-tasks. JH suggested gender be considered in planning and delivering home care for people with mental illness.

Carol noted that people who notice a neighbour in difficulty can take a role in ensuring that people get help when they need it. She has the advantage of living in a small community and knowing who to contact to alert the system. She also noted limited availability of mental health services in rural Saskatchewan because trained personnel is not available. Coordination in accessing and offering services is also a concern in urban Ontario.

FB, a community service worker in a First Nations community in Manitoba gave thoughtful answers to the questions about home care and mental health. Her experience is that mandate for home care services do not include the most pressing service needs of mental health clients. She suggested the addition of consumer proctors who could offer services for people who experience mental illness. And she emphasized that funding for training as well as service delivery would be needed to allow for services specific to mental health clients.

Assessment

Lady Guinevere reflected on aspects of assessment and care planning that she has noticed as a recipient of home care services. She encouraged a range of assessment approaches including the consumer and formal and informal support people to accurately determine the full range of needs and supports. She urged both consistency and flexibility in the services and the home care workers.

N.S. confirmed that mental health assessment is particularly important for person with physical illness as well as clients with psychiatric diagnoses.

M.W. reported that home care for persons with mental illness is being introduced in Western Newfoundland and reflects on the need for a comprehensive and flexible range of resources from outreach workers, and workers who can help with everyday tasks from cooking and laundry to shopping and keeping appointments.

Cheylou commented on the unique features of assessments of persons with mental illness with varying severity. She also urged assessments of the care plans and evaluations of agency performance.

Nona from Quebec reported that psychiatric diagnosis is not as useful for assessment as Behaviour/Risk assessment which is more inclusive and helpful for identifying the kinds of services that might benefit the client. The Psychogeriatric and Risk Behaviour Assessment Scale (PARBAS) rates the frequency and consequences of self-neglect, risk to self and others, emotional distress, suicidal behaviour, personal and financial security as well as availability of informal support in setting intervention priorities.

This risk assessment suggestion was questioned on the grounds that it feeds into the stigma of danger and misunderstanding of mental illness. Cheylou adds the reminder that remaining calm with soft voice and patience reduces the risk.

Stephanie warned that assessment that focuses only on the most severe cases may leave out other consumers who could benefit from support.

Lady Guinevere emphasized that assessment is a recurring and ongoing process.

Informal / Family Caregivers

In May 2004, a Health Canada report *Informal/ Family Caregivers in Canada Caring for Someone with a Mental Illness*[7] was released. In a survey of 343 caregivers, Decima research found that about half of the caregivers agreed that additional formal assistance would be of help to them, primarily with psychological services and homemaking duties. Those caring for a family member other than their child were more likely to express a need for formal assistance.

Although the Family/ Informal topic area did not have postings, the topic was covered in other discussions. Cori noted that access to professional care reduces the danger of family and friend burn-out in dealing with people who leave the hospital and return to the community. Lady Guinevere also noted that formal and informal caregivers have different roles and are both necessary.

Stephanie reminded the forum that not everyone has friends and family and this should be taken into consideration in offering mental health home care.

Kent from near Saskatoon, Saskatchewan said 'the most bang for the buck' is found in consumer run drop in centres and programs.

Kent also indicated concern about the potential for abuse in mental health care. Abuse of persons with disability can come from family and friends, through unethical service providers and from elements in society that take advantage of vulnerable persons. Home care workers can feel uncomfortable about working with persons with mental illness, and consumers may fear letting people into their homes. In addition, home care workers may become aware of abuse (physical, emotional, sexual, economic) that threatens their clients and need to know the avenues for gathering information, reporting, and preventing further harm.

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[7] An earlier report *National Profile of Family Caregivers in Canada – 2002*is available at http://www.hc-sc.gc.ca/english/care/nat_profile02/2.html *Caregivers … for Mental Health* is not on the Health Canada website (as of April 2005).

Human Resources

Carol, an RN [Registered Nurse] from Saskatchewan, who is presently developing teaching materials for health professionals noted that although their education touches on mental health issues, many professionals including home care workers do not have particular training in psychiatric nursing.

Carol goes on to note that informal and formal caregivers can work together to make sure people get support when then need it. Carol noted the barriers of stigma and the need for community education:

Dick offered the services of the Gay, Lesbian, Bisexual and Transsexual (GLBT) community to assist with training workers to meet the mental health needs of this population, and with retired older adults. Dick emphasized that service providers need to be particularly aware of the need for sensitive, non-judgmental attitudes in working with people who may feel more vulnerable because of their lifestyle as well as the stigma of mental illness. Lady Guinevere pointed out that many different groups would benefit from awareness, flexibility and respect in meeting their physical and emotional needs. Lady Guinevere went on to describe a program offered through the Independent Living Resource Centre in Winnipeg to train home care assistants, particularly those who work directly for clients in programs of self-managed care.

Eva told of a program of Community Health Workers in Vancouver to ensure that consumers get their medications regularly and maintain their functioning. Cheylou has concerns about a program that focuses on ensuring that consumers take their psychiatric medications. She cites the needs for other kinds of follow-up, for guarding against abuse of medication (by patients but also by prescribers), and for responsibility in awareness of the side effects and other health dangers of psychiatric medications.

An offer of support and experience came from a program in Ontario that has experienced the challenges of integrated services provided by home care and mental health organizations. N.S. reflected on the difficulties of pulling together the home care system and the mental health system to meet the psychiatric needs of their clients including philosophical differences, lack of common language, salary differences between programs, and the low importance put on mental health services.

G.R., a case manager from Cornwall, Ontario suggested that home care and mental health workers should be aware of the possibility of addictions as they provide their home care services. This comment caused Stephanie to raise the issues of privacy and respect. G.R. responded that he hoped the monitoring would improve the assistance available to a person with mental health and addictions disorders.

Accountability

N.S. is involved in an internal research project to determine accountability measures for positive outcomes in community mental health. Standards must be suitable for a range of

services for people who experience a range of severity of mental illness symptoms. Adequate funding is an issue in the provision and evaluation of any services.

The next section pulls out the key findings from the web discussion and looks at the possible federal policy implications and potential next steps for CMHA in cooperation with the Canadian Home Care Association and other partners.

Findings, Policies, and Next Steps

We share our experiences through our stories. The web discussion drew out a number of stories and personal experiences. In this section, stories, observations and concerns must be summarized and reformulated into generalized findings. Less attention is paid to individual details in order to capture the main themes. The purpose of this web forum was to continue a policy dialogue for the next phase of decision-making on concrete advice to the federal government on home care for consumers with mental illness.

This table presents key findings raised in the web discussion held in February and March 2005. Policy implications, though aimed primarily at the federal level, may be useful for provincial/ territorial and even regional levels as they plan and implement home care for persons with mental illness. The Possible Next Steps puts forward potential projects for CMHA in cooperation with the Canadian Home Care Association and other interested partners. Every person who reads this report is challenged to consider mental health and mental health home care (MHHC) in all discussions of strategies, policies and planning for the continuum of health care.

	Theme Area	Finding	Policy Implication	Possible Next Steps
1	Access Assessment Family HR Accountability	MHHC[8] is only one component of a mental health continuum, linked to other resources and programs.	Develop a comprehensive mental health policy and infrastructure / strategy that includes home care as part of an integrated continuum from prevention to primary and acute care to respite care to long term institutional care.	Work with CAMIMH[9], national and provincial groups to develop a national mh strategy. Build on the work of the Kirby Senate Committee[10]. Keep mental health and MHHC on agendas of all health strategy development.

[8] Abbreviations used in this table: Mental Health Home Care shortened to MHHC. In the physical disability community, the emphasis is on a person's Ability, as reflected in the symbol of d/A. F/P/T refers to Federal, Provincial, Territorial agreements worked out by prime minister, premiers, and territorial leaders. C/S abbreviates "consumers"; mh means mental health.

[9] CAMIMH Canadian Alliance on Mental Illness and Mental Health: The founding members of CAMIMH are: the Mood Disorders Association of Canada, the Schizophrenia Society of Canada, the National Network for Mental Health, the Canadian Mental Health Association and the Canadian Psychiatric Association. These five family, consumer, community and professional groups collaborate as the core coordinating group. They are building consensus for a national action plan on mental illness and mental health. http://www.cmha.ca/english/research/camimh.htm

[10] Senator Michael Kirby, *Reforming Health Protection and Promotion in Canada: Time to Act (2002).* http://www.parl.gc.ca/37/2/parlbus/commbus/senate/com-e/soci-e/rep-e/repfinnov03-e.htm . Results of hearings will be published early 2006.

2	Access Assessment Family HR Accountability	Comprehensive MHHC must be mandated and supported by policy, management and appropriate funding.	A 10-year F/P/T plan has begun the process, and must be enhanced and monitored to ensure provincial and regional implementation.	A Policy Forum to involve and support high level policy management from the federal, provincial and territorial governments to define and agree to the current and future scope of MHHC before the planning and implementation
3	Access	Stigma, fear and misunderstanding of mental illness erect barriers for consumers, caregivers & public.	Ensure legislation, policies and regulations are respectful and inclusive for persons with mental illness.	Continue public education and awareness to combat stigma.
4	Assessment	Services need to see and help the person, not the diagnosis or many diagnoses.	Mandate communication, coordination, and funding possibilities among services and specialties.	Some provinces are integrating mh and addictions services. Pull together leaders from mental health, addictions, chronic diseases and d/A for a "Whole Person" conference.

5	Assessment Family HR	Consumers and families live daily with the challenges of mental illness.	Ensure adequate supports for the consumer and family are convenient for recipients, as well as providers.	Strengthen the C/S and family voices in planning, implementing and evaluating programs. Build MHHC into the national caregivers strategy.[11]
6	Family HR	Formal and informal advocates can support individuals, make links with available services and champion needed solutions.	Encourage innovators and quality control awareness to champion better ways of delivering service and meeting needs. Empower formal and informal advocates.	Accept nominations for an Intersectoral Advocate and Champion Award.
7	Assessment HR Accountability	Mental health care is more than medication. More medication can be the problem, not the solution. MHHC must include monitoring and communicating with other professionals about medication results.	Strengthen the Health Canada monitoring of psychiatric medication safety and prescribing; develop reporting mechanisms for drug reaction and interaction.[12]	"Mental Health is More than Meds" awareness campaign to promote continuum of services and community involvement.

[11] The Canadian Caregivers Coalition http://www.ccc-ccan.ca/index.php has drafted a working paper for a Canadian Caregiving strategy.

[12] Health Products and Food Branch Consumer and Public Involvement Framework http://www.hc-sc.gc.ca/hpfb-dgpsa/ocapi-bpcp/piframework_cadrepp_e.html

8	Family HR Accountability	Community mental health involves the whole community: neighbours, social groups, activities and employment.	Implement accountability to ensure that case management coordinates mental health services, health services, home care and informal supports in needs-based care.	Find, develop and promote best practices for the role of MHHC in integration of C/S into community. Build and highlight "communities of excellence" where a Framework for Support of formal and informal relationships promotes recovery and quality of life for c/s, families and all citizens.
9	Access Family HR Accountability	Housing with appropriate supports is integral to MHHC.	Homelessness initiatives must address needs of persons with d/A including mental illness.	A Mental Health, Housing and Home Care consultation
10	HR	Train professional caregivers for home care with persons with mental illness.	Find and/or design MHHC training; fund training; establish common standards of practice. Integrate and/ or enhance MHCC into current curriculum and training.	Bring together health educators with C/S, families and workers in mental health, home care & community services to outline training including a common language.
11	Access Assessment Family HR Accountability	Different populations may require particular attention: • persons with severe, chronic psychiatric symptoms • seniors having difficulty at home • youth and young parents • people with physical d/A • persons with addictions • First Nations • Immigrant & Refugee • people who feel vulnerable by reason of sexual orientation, etc.	The pan-Canadian Health Human Resources Strategy[13] aims to ensure a health-care workforce to meet the needs of all Canadians. Recognize that MHHC requires "tailor-made" flexibility. This is not a "one size fits all" business. Emphasize respect and acceptance as a requirement for MHHC providers.	Actively encourage representation from these and other cultures/ populations to any consultation. Human Resources for MHHC promote training in the best mental health and the best home care practices. Involve consumers and families as researchers and educators, including those who can focus on culturally sensitive services (ethnic, race, addictions, GLBT, physical d/A, etc.) Investigate models of service delivery including self-directed and the Manitoba proctor program.

[13] The Health Human Resource strategy focuses on three critical areas: 1) Planning ; 2) Recruitment and Retention; and 3) Interprofessional Eduation For Collaborative Patient-Centred Focus http://www.hc-sc.gc.ca/english/hhr/index.html

12	Access Accountability	Access to services is limited for both rural and urban populations. Don't forget First Nations people, on and off reserve.	Maintain goal of "universal" health care services in planning MHHC and all mental health and home care services.	Continue and strengthen advocacy.
13	Assessment Accountability	Assessment for mental health needs may require additional tools, training and process.	Work with provinces and territories to agreement on a minimum data set that allows research to establish general and specialized assessment strategies for MHHC – evaluate the tools, the delivery and the outcomes.	Evaluation of existing tools, delivery and outcomes of MHHC.
14	Family HR Accountability	Informal/ family caregivers have a different role than formal service providers in the well-being of consumers. Formal caregivers can help prevent burnout in family and friends.	Implement policies of financial compensation, respite, and recognition for informal caregivers.[14] Evaluate policies that assume that family will provide necessary care if services are not provided	Work with Caregiver and Consumer groups to develop a national strategy for informal caregivers, e.g.. the Schizophrenia Society is concerned about adult children with mental illness whose elderly parents can no longer provide care.
15	HR Accountability	Roles and tasks for MHHC need to be explored, and documented with outcome measurement in the implementation and development stages and on an ongoing basis	Establish a common understanding of the definition and scope (the basket of services) included in needs-based service provision for MHHC. Establish a common set of indicators for monitoring and evaluation.	Roles and tasks for MHHC need to be explored, documented, and evaluated on an ongoing basis.
16	Accountability	Accountability and Performance Indicators for the F/P/T Advisory Network on Mental Health have been developed.	Evaluate the Accountability process to ensure the indicators are valid for quality in both mental health and home care. Ensure adequate funding for ongoing evaluation and for sharing evaluation results and best practices for further development.	Work with the Canadian Council of Health Services Accreditation to develop a program of C/S and family trained to evaluate and serve on Accreditation Teams for MHHC provision (and other services).

Recommendations

The Possible Next Steps suggest short term and long term projects that might be undertaken by CMHA and interested partners.

[14] The Canadian Caregiver Coalition http://www.ccc-ccan.ca/index.php is currently developing a briefing paper on caregiver compensation.

Policy Forum

As a Next Step, a Policy Forum would provide an opportunity to involve and support high level policy management from the federal, provincial and territorial governments to define and agree to the current and future scope of MHHC before the planning and implementation of home care with persons who are mentally ill.

Invite policy makers for home care and for mental health from each jurisdiction. With consumers and family members, these officials would develop common values and processes that set the foundation for a effective system of mental health home care. The Policy Forum would provide opportunities for decision makers to share their strategies and build collaboration between sectors and across the country.

The goal: to build an effective mental health home care initiative in a comprehensive continuum of mental health services.

A number of questions need to be considered before beginning and/or expanding a mental health home care program.

Your Next Step

Organizations and individuals who are involved in health care reform, home care, mental health, and related concerns are encouraged to adopt and promote next steps (from the chart above or their own ideas) to support the mental health home care initiatives.

For example, the role and contribution of mental health home care might be considered in negotiations on various strategies currently under consideration. For example,

- National Mental Health Strategy
- Caregiver Strategy
- Health Human Resources Strategy
- Chronic Disease Strategy[15]
- Healthy Living Strategy[16]

In addition, mental health and home care issues are relevant to the ongoing Senate commission hearings on mental health[17], as they were in the report of the Romanow Commission on the Future of Health Care in Canada[18]

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[15] The Public Health Agency focusing on Chronic Diseases does not mention mental illness http://www.phac-aspc.gc.ca/media/nr-rp/2004/who_2004bk_e.html

[16] Healthy Living Strategy http://www.phac-aspc.gc.ca/hl-vs-strat/index.html

[17] Senator Michael Kirby, *Reforming Health Protection and Promotion in Canada: Time to Act (2002).* http://www.parl.gc.ca/37/2/parlbus/commbus/senate/com-e/soci-e/rep-e/repfinnov03-e.htm . Results of hearings will be published early 2006.

[18] Romanow Commission http://www.hc-sc.gc.ca/english/care/romanow/index1.html

In addition, many provinces and regions are involved in reform and planning of their health care delivery, conducting consultations and developing policies. The questions in Appendix D[19] may be useful in planning mental health home care in your jurisdiction.

The Canadian Mental Health Association at the national, division, and branch levels may see a Next Step that they would choose to champion. Other organizations of consumers, professionals, and community interests can raise awareness of the needs for consultation and planning in development of mental health home care.

Reading this report is one step. What is *your* Next Step?

Conclusion

The Web Discussion seemed to re-engage only two or three of the more than 50 participants from the Home Care Sector and Mental Health Forum in continued discussion. It did add new voices of consumers and advocates who had not been at the Policy Forum. The small number of participants (21) does not represent the many stakeholders who are affected by policies and programs that may be developed in this area. However, most of the posts were thoughtful and relevant..

The reason for this small sample is not clear. One Steering Committee member became aware that the announcement of the web site publication of the Forum Report had been buried in the Web Discussion invitation, and that some Forum participants felt that they had not received the previous report so were reluctant to re-engage in the process. Another suggestion was that the discussion took place during the period when most agencies are at fiscal year end, and the managers who might have responded were engaged in that priority. A person who attended the Forum told the Facilitator that she felt she had said her piece then and that there was nothing she wanted to add to the web discussion.

Analysis of the discussion emphasized some of the points that are already on the agenda including the need for a continuum of mental health services, the problems of stigma, and the need to plan and prepare both mental health and home care for this cross-sectoral program.

A variety of approaches are needed to move forward the policy and program development for a comprehensive mental health system that includes home care services, or a comprehensive home care system that includes mental health services. Some of the basic questions remain to be sorted out. Specific issues of access, assessment, the roles

[19] Appendices and the quotes from the web discussions are available in the full *Home Care and Mental Health Web Discussion: Next Steps* Report at www. cmha.ca

of informal and formal caregivers, and the evaluation of services will be the subject of discussions at many levels as Mental Health Home Care is implemented.

As Cheylou said, "Establish parameters for average situations but allow exceptions for the rare and difficult cases. Do not conform to one view on methods of delivery of home care for most cases either. … All people must be given an opportunity that may work, even though many other attempts have failed."

That's true for people with mental illness, but it also applies to web discussions and mental health home care.

The Short Version of the Home Care and Mental Health Web Discussion: Next Steps Report is available from CMHA National www.cmha.ca