

<b>POLICY TITLE</b>	<b>Policy Category/Number</b>	HCS-210.3
<b>Family Member and Natural Support Participation in Mental Health Service Planning, Implementation and Evaluation</b>	<b>Date Approved</b>	May 2005
<b>Branch/Division</b>	<b>Applicable to</b>	Regional Health Authorities Selkirk Mental Health Centre
<b>Responsible Authority</b>	<b>Review Date</b>	January 2007
Mental Health & Addictions Policy, Program & Agency Relations/ Healthy Living	<b>Date Revised</b>	May 2005
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**1.0 POLICY STATEMENT**

Whereas responsiveness to the needs of consumers and their families is the ultimate goal of all services, mental health planning, implementation and evaluation must reflect a variety of perspectives including those of family members and other natural supports. With the informed consent of the individual, family members and other natural supports will be encouraged to play an active role in processes that affect the lives of those living with mental illness.

**2.0 BACKGROUND**

Family members and other natural supports are among those with the most informed experience and passionate concern for the development of effective mental health services. This policy builds on the work that was done during the process of reform of mental health services in Manitoba, which began in 1988. In 1990 the document *Vision for the Future: Guiding Principles and Policies for Mental Health Service Providers* was developed which included the fundamental principle that "mental health services shall augment and reinforce helping networks in the community such as family, friends, clergy and self-help groups as well as other government departments and agencies." In 1992, the document, *Building the Future of Mental Health Services in Manitoba*, was developed which emphasized the principle that "local citizens, consumers and communities shall participate in the planning, development and delivery of mental health services to community members."

This period marked the beginning of significant implementation of the proposed elements of family member participation and collaboration between Manitoba Health, self-help groups, Regional Mental Health Councils, the Advisory Committee on Mental Health Reform, service providers and recipients of mental health services and their families.

The vision and goals for Mental Health Renewal were developed in 2002. One of five goals of Mental Health Renewal is to continue to enhance and expand the role of family members and other natural supports in the mental health system. One of the statements within the vision of Mental Health Renewal is, "Family members and other natural supports are included in the planning and evaluating of services and initiatives." In addition, "Self-help groups play a significant role in the mental health system and in the lives of consumers, family members and other natural supports." Family members and other natural supports play a significant role within self-help agencies.

The first goal of Mental Health Renewal was developed as follows:

*"Enhanced, meaningful involvement of consumers, family members and other natural supports in individual services and health system planning." (Manitoba Health, 2002).*

The second goal of Mental Health Renewal was developed as follows:

*"Enhanced role of self-help groups in the mental health system and in the lives of consumers, family members and other natural supports." (Manitoba Health 2002)*

In personal accounts of consumers the support provided by others, including family and friends has often been identified as a key dimension of recovery. (*Mental Health Recovery, What Helps and What Hinders? 2002; The Last Taboo, 2000*) The overall social response to mental illness involves much more than the formal mental health system. It involves consumers themselves, family members and other agencies and sectors. In this broader context, families emerge as the single largest group of caregivers in any particular community in Canada (*Building a Framework for Support, 1999*).

This Family Member/Natural Support Participation in Mental Health Service Planning, Implementation and Evaluation policy has been developed by Manitoba Health in consultation with the Provincial Mental Health Advisory Council (PMHAC). The membership of the Council is composed primarily of consumers and family members.

### 3.0 PURPOSE

To provide direction to Regional Health Authorities (RHA's) and the Selkirk Mental Health Centre (SMHC) in the development of their plans for meaningful family member and natural support participation that will:

- offer support to family members and other natural supports;
- enhance opportunities to work towards authentic working relationships between consumers, family members, other natural supports, service providers, mental health managers, system planners and policy makers; and
- improve the quality of services and consumer satisfaction through effective mental health service planning, implementation and evaluation.

### 4.0 DEFINITIONS

- 4.1 Consumer Participation:** either voluntary or paid participation by consumers in formal or informal planning, delivery and evaluation of all activities associated with mental health services, as well as in all processes that affect their lives, through the sharing of information, opinions, and decision making power.
- 4.2 Consumer:** an individual who accesses mental health services.
- 4.3 Family Member:** for the purposes of this policy "family member" will refer to members of the consumer's nuclear or extended family or significant other whom the client defines as family.
- 4.4 Natural Support:** an individual (family member, friend, etc.) who plays a significant role in offering support to a consumer(s). A natural support is not necessarily a part of the formal care system and is not remunerated for offering this support. This may include individuals from a broad network of social support, e.g. friends, clergy.
- 4.5 Recovery:** is an ongoing process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with limitations caused by an illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the effects of mental illness. (Anthony)

## 5.0 POLICY

Plans developed by RHA's and SMHC for enhanced participation of families and natural supports will be based on the core values of:

- respect;
- collaboration and participation; and
- shared responsibilities.

Plans will include opportunities, strategies and resources to facilitate the participation of family members and natural supports. This participation in mental health system planning and service delivery should include the full range of opportunities including active dialogue, implementing participation activities and establishing authentic collaborative partnerships.

It is expected that these plans will incorporate:

- multiple participation activities; and
- a range of activities along the participation continuum (listening, involvement, partnership) that address all areas of effective family member and natural supports participation.

### **The key areas to be included in the plans are:**

#### **1) Policy**

Plans will include a process for input from family members and other natural supports in the development of policy. This may include the development of a local family participation policy.

#### **2) Planning/ Service Development**

Plans will include a process for significant family member/natural support representation in any forum in which services are being planned and/or evaluated that will affect the lives of consumers.

#### **3) Direct Service**

Consistent with privacy legislation, service providers will encourage family member involvement in intervention planning and the recovery process when both provider and consumer agree that it would be helpful and with the informed consent of the consumer.

#### **4) Resources**

Resources will be provided to enable effective family member/natural support participation. Such resources may include the following:

Instruction in the process of meetings, government processes, best practices in mental health planning and service delivery, leadership skills development for family members/natural supports; encouragement and support of programs such as self-help/peer support for family members/natural supports, advocacy groups, networks and respite.

#### **5) Information**

An effective communications strategy to inform family members/natural supports of services and supports available to consumers, to family members and to other natural supports.

A process to clearly communicate the purpose, and specific opportunities for family member/natural support participation to consumers, family members, other natural supports and service providers.

#### **6) Complaints Mechanism**

A formal complaints mechanism will be in place that is made known to consumers, family members, natural supports and service providers.

## **7) Employment and Training**

Experience as a family member or other natural support will be considered an asset for employment, when the potential employee has met job requirements. Training will be provided to staff regarding effective collaboration with family members/natural supports. Changes will be made, if required, to the work environment to support family participation.

(See Appendix 1 for models of participation activities in Manitoba and in other jurisdictions).

## **6.0 CORE SUPPORTING DOCUMENTS: Standards, Procedures, Guidelines**

### Procedures

#### **A. Manitoba Health**

- In consultation with the Provincial Mental Health Advisory Council, develop the provincial policy for meaningful family member/natural support participation.
- Consult with Regional Health Authorities on the draft policy.
- Establish and communicate expectations to RHAs and SMHC.
- In consultation with the Provincial Mental Health Advisory Council and the Regional Health Authorities, review and revise the policy biannually.
- In consultation with the Provincial Mental Health Advisory Council, evaluate the effectiveness and impact of the family member/natural support participation policy.

#### **B. Regional Health Authorities and Selkirk Mental Health Centre**

- In consultation with family members, other natural supports, consumers and self-help, develop participation plans in their respective regions/Centre that are consistent with the provincial policy.
- Submit plans to Manitoba Health.
- Communicate participation opportunities to family members, natural supports and consumers.
- Implement family member/natural support participation activities.
- Evaluate effectiveness of participation activities, with family members, other natural supports, consumers and self-help on an annual basis.
- Submit a participation inventory to Manitoba Health biannually.

## **7.0 POLICY DOCUMENTS**

### **7.1 APPENDIX A: EXISTING FAMILY PARTICIPATION ACTIVITIES IN MANITOBA AND IN OTHER JURISDICTIONS**

## **8.0 REFERENCE DOCUMENTS**

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Existing Family Participation Activities in Manitoba and in Other Jurisdictions

**There are many illustrations locally, provincially and internationally of meaningful family participation.**

**Policy**

1) In Manitoba, the **Provincial Mental Health Advisory Council** was re-established in 2002 to provide advice and feedback to the Minister of Health and the Council of CEOs of Regional Health Authorities from a mental health consumer and family member and other natural supports perspectives. The Council's terms of reference indicate that people with mental illness, family members and other natural supports will constitute at least 75% of Council membership with consumers of mental health services constituting a minimum of 60% of this 75%. It meets a minimum of four times a year and its purpose is as follows:

To provide advice and feedback to the Minister of Health and the Regional Health Authorities from mental health consumer, family member and other natural supports perspectives. To that end, the Council will:

- a) provide a forum for the discussion of a broad range of health and human service issues that impact on the lives of people with mental illness and their support networks from the perspective of consumers, family members and other natural supports;
- b) develop strategies in regards to the capacity building of people with mental illness to play an increasing role in providing input into the planning, implementation and evaluation of regional services and provincial initiatives;
- c) provide advice to the Minister of Health, through Manitoba Health, and Regional Health Authorities, through the Chief Executive Officers Council and through the link between Manitoba Health and the Mental Health Managers Network of RHAs that reflects the vision, values and principles set out in the Terms of Reference;
- d) reinforce the need for communication, coordination and collaboration in the interests of providing seamless services;
- e) provide creative thinking from consumer and family member perspectives to issues that are identified in health and human service systems by Manitoba Health, the Minister of Health or the Regional Health Authorities.

The Council has been instrumental in the development of a consumer participation policy currently in effect across the Province. The group provided input and shaped the policy from a consumer and family member perspective. It worked on the consumer participation policy with the Mental Health Branch for 1 1/2 years. The Council is now doing the same work on this family and natural supports policy. The Council has been an effective mechanism for meaningful consumer and family member input into the development of provincial policy to support Mental Health Renewal.

2) **The Mental Health Council of Australia**<sup>1</sup> has published a Consumer and Carer Participation Policy Template to guide the development of policy that aims for participation that leads to strong partnerships. The following components were selected for inclusion in a consumer and carer participation policy.

- a) The purpose of the policy should be clear, achieved through a concise statement of purpose.

<sup>1</sup> Mental Health Council of Australia (2002). Consumer and Carer Participation Policy Template.

- b) The policy should be grounded by a set of principles that reflect the value the organization places on consumer and carer participation. For example:
- Consumers and carers have a right to participate and have a direct and active role in all processes that affect their lives.
  - Consumers and carers with appropriate skills and expertise should be appointed to represent the interests of consumers and carers.
  - Priority should be given to the appointment of consumers and carers who are members of groups able to provide support and a network for consultation.
  - A single person should not be appointed to represent the views of both consumers and carers. Both a consumer and a carer representative are required to represent the views of each respective group.
  - Participation of consumers and carers is an essential component of continuous quality improvement.
  - Communication links between the organization and consumers and carers are effective two-way processes.
  - Information is shared and exchange with consumers and carers to enable effective participation.
  - The organization recognizes the need for resources and support for the consumer and carer participation process to enable effective participation.
  - Opportunities are provided for the ongoing support and relevant training and education for consumers and carers to assist in their effectiveness as consumer and carer representatives.
  - Consumers and carers must be aware that responsibilities are associated with participation, primarily the active contribution to quality improvement processes.
- c) The policy should articulate the organization's position in relation to consumer and carer participation in:
- Strategic planning
  - Service delivery
  - Service implementation
  - Service evaluation
  - Health decision-making and
  - Resource allocation
- 3) The policy should state:
- The responsibilities of all parties in implementing the policy;
  - What measures will be taken to monitor the policy's implementation;
  - When the policy should be reviewed; and
  - How the policy will be evaluated

## **Planning/Service Development**

### Specific Service Feedback and Surveys

The Canadian Mental Health Association - BC Division undertook surveys (funded by the Ministry of Health and Vancouver Coast Health Authority) of consumers, family members, service providers, family doctors and other key external groups (ambulance, RCMP, child and youth serving agencies, etc). Rather than doing surveys of each group in separate processes, they have undertaken similar surveys across these groups which are incorporated into this

Coast Garibaldi Adult Mental Health System Progress Report. The goal of the system evaluation was to collect information from a wide range of respondents including consumers of mental health services, family members, service providers and external groups about adult mental health system functioning throughout the region and then to use the information collected as the basis for system improvements. The full report and a summary version were completed November 2002 and distributed with an aim at looking at next steps toward system reforms. It is available at <http://www.cmha-bc.org/content/resources/research/research.htm>.

## Direct Service

### Policy of the Department of Developmental and Mental Health Services on Family and Consumer Involvement, Vermont

*This policy on family and consumer involvement was written and endorsed by a committee made up of representatives from the National Alliance for the Mentally Ill of Vermont, the Vermont Council of Community Mental Health Services, and the Department of Developmental and Mental Health Services. The policy is intended to involve families of adults with severe mental illness according to the standard of the core support capacity named “Family and Consumer Involvement,” which reads as follows:*

*“Since responsiveness to the needs of consumers and their families is the ultimate goal of all services, consumers and families will be actively involved in the local planning, implementation, and evaluation of the core service capacities.*

The policy of the Department of Developmental and Mental Health Services is that family involvement is to be encouraged because it is presumed that such involvement has important therapeutic benefits. It is essential that this policy be applied, and confidentiality laws do not bar its application.

What this means in individual cases is that families\* are to be made part of the treatment process, absent the expressed refusal of the client or compelling evidence that such involvement would be counter-therapeutic. There obviously may be questions in individual cases about what material might be revealed, but, as a general rule, confidentiality laws do not bar family involvement in efforts to treat clients and such involvement should be the norm rather than the exception.

Families in the role of caregiver should know, at a minimum, the importance of ensuring that clients take their medication and what side effects might occur. Families also should be told what signs or symptoms to look for if the client does not comply with treatment or take prescribed medication, or if his or her condition begins to deteriorate. Caregivers, including families, should know the special needs of clients who are living with them while receiving follow-up outpatient or day care treatment.

Any perceived potential for dangerous behavior to self or others should be discussed. Mental-health professionals should also encourage family members and other caregivers to report to the treatment source—the treating psychiatrist, other mental-health professional, or outpatient clinic—any changes in the client that may be significant and relevant to future behavior. A clinician should actively enlist the family with whom the client is most involved as a source of information about compliance because the family may be the best source of information.

On the other hand, we do not suggest that details of conversations between clinician and client should be revealed, nor do we suggest that other material not relevant to the families’ role as caregiver be divulged. Such details lie at the heart of the confidentiality principle.

The disclosures to and exchanges with families would be preceded by a discussion with the client on the value of these communications and by obtaining the client’s consent. We do not suggest that families be involved regardless of client’s choice; however, when the client withholds consent to share information, the therapist should work with the client to understand the reasons for the refusal and help the client accept family collaboration.”

\*Family is first-degree relative or other significant others whom the client defines as family.

## Resources

- 1) Family\* Resource Centre, Centre for Addiction and Mental Health (CAMH), Toronto, Ontario



\*Family here means “any spouse, partner, friend or relative who is close to the consumer and/or helps the consumer through treatment”.

The Centre for Addiction and Mental Health (CAMH) in Toronto has a Family Council, a Family Resource Centre and a Family Outreach and Response Program.

“Family members are important partners in treatment. With your consent, CAMH staff will inform your family about your progress. A social worker is available to discuss family concerns, and support groups are available for family members. We often offer education to help you and your family understand and deal with addiction or mental health problems. Educational literature is also available.

Family members can participate in relevant Centre committees through the Family Council. To learn more, please call our Family Council Coordinator (416) 535-8501, ext. 6499. .

The Family Resource Centre is staffed by volunteers who have experienced the impact of mental illness on their own families and friends. They can give you education, emotional support or information about available resources. To speak to a trained family volunteer at the Resource Centre, please call: (416) 535-8501 ext. 4015.

The Family Outreach and Response Program offers telephone and group support, and holds educational events for anyone who has a relative, spouse or friend receiving services at the Centre. Please call: (416) 535-8501 ext. 2011.”

From the website: [http://www.camh.net/care\\_treatment/care\\_patientsguide2.html](http://www.camh.net/care_treatment/care_patientsguide2.html):

## 2) Leadership Skills Development

In 1992, Australian Health Ministers agreed to the National Mental Health Strategy in which the participation of “consumers” and “carers” in decision making was recognized as a key value for mental health reform. Under this strategy the Community Development Project was funded with the goal of anchoring the role of consumers and carers in the mental health system.

In support of this strategy, the **Mental Health Council of Australia** developed "The Kit" which includes two sections: 1) Knowledge and Attitudes and 2) Skills, Strategies and Tools containing five subsections of 'How To' information including topics such as: Being a committee member, Starting up a group, Creating networks, How to influence people etc. The kit can be accessed through email [admin@mhca.com.au](mailto:admin@mhca.com.au) or see the web site at <http://www.mhca.com.au/public/communitydevelopment/thekit.htm>.

More information about the Mental Health Council itself can be found on its website at: <http://www.mhca.com.au/>.

## **Information**

### **1) Code of Family Rights**

The **Taranaki Mental Health Services** (Taranaki District Health Board, New Zealand) has a Code of Family Rights in place. The Code is for the family of a person who either has, or may be developing a major mental illness.

The Code advocates the right to:

- A family centred approach to treatment and support.
- Culturally accepted treatment options that are inclusive to the family.
- Be treated with understanding and respect.

- Be taken seriously when expressing concerns about changes in a relative's behaviour.
- Rapid response in all situations, but especially in an emergency.
- Provide relevant information about a family member's history, in confidence.
- Information about a family member's diagnosis, treatment and possible side effects of treatment.
- Seek other opinions regarding the diagnosis and treatment of a relative.
- Inclusion in care planning, implementation and review.
- Information on the range of relevant services and supports available in the community.
- Help for problems created by caring for a family member with a mental illness.
- Time out when required to prevent 'burnout' or to cope with stress.
- Be consulted about a family member's discharge plan.
- Know the names and contact phone numbers of other members of the care-giving team.
- Mechanisms of complaint and redress.
- A mental health service that recognises the need for families to participate in shaping the service and invites families to take part in service planning, implementation and evaluation.

More information about the **Taranaki Health** Family Participation Policy, Family Advisor and Support Groups and their complaints process can be accessed at [www.mentalhealthinsight.org.nz](http://www.mentalhealthinsight.org.nz).

2) The **Mental Health Education Resource Centre** of Manitoba has recently produced guides for family members of those living with mental illness to provide information on various services and supports and to provide answers to frequently asked questions.

### Complaints Mechanisms

1) Many **Regional Health Authorities** in Manitoba have a designated Client Relations Manager for community health programs to manage the complaints process.

2) In Winnipeg, the **Canadian Mental Health Association, Winnipeg Division** has one staff position dedicated to individual advocacy. "The Advocate" is responsible for assisting consumers of mental health services with accessing services or making complaints about services. Although the Advocate would not have responsibility for opening a file and following a family member, he or she would be able to provide general information and advice to a family member or natural support.

3) **Selkirk Mental Health Centre** has its own internal complaints process, as well as a designated Patient Advocate position. The Centre also publishes a Patient's Rights brochure with information for patients including explanation of their right to speak personally with the Ombudsman, Legal Aid, The Public Trustee or the Protection for Persons in Care Office. The Centre also publishes a Family Brochure with information for families. Family Self-Help Groups meet monthly and families have access to a Resource Centre with newsletters, workshops, videos and books.

4) Self Help Organizations e.g., **Schizophrenia Society, Mood Disorders Association**, etc. are independently run groups that receive some government funding and whose mandate includes peer support and public education as well as individual and system advocacy on behalf of consumers and their families.

### Employment and Training

The Center for Psychiatric Rehabilitation at Boston University has a kit entitled "What Professionals need To Know About Families"<sup>2</sup> available. The set of 5 training modules was developed to teach professionals how to work more effectively with family members

<sup>2</sup> Spaniol, L, & Massachusetts NAMI/DMH Curriculum, Training and Practice Consortium. (2004). What Professionals need To Know About Families. Boston: Boston University Center for Psychiatric Rehabilitation.

The modules are:

Module 1: The Family Experience of a Family Member with a Psychiatric Disability

Module 2: Changing Family Roles

Module 3: Family and Practitioner Needs for Information, Skills and Support

Module 4: Family/Professional/Consumer Collaboration

Module 5: The Role of Family Members in Recovery

The entire kit which includes training content and guidelines, recommended readings, exercises and pre-and post-evaluation exercises is available on pdf format and can be ordered on line at <http://www.bu.edu/cpr/catalog/index.html> or by phone at (617) 353-3549. The kits can also be borrowed in Manitoba from the Mental Health Education Resource Centre (204) 772-4917 or [info@mherc.mb.ca](mailto:info@mherc.mb.ca).