

**B.C.'s Mental Health Reform**

**FAMILY SUPPORT  
AND INVOLVEMENT**

**BEST PRACTICES**



**BRITISH  
COLUMBIA**

Ministry of Health and  
Ministry Responsible for Seniors

This report is one of seven mental health best practices reports. The reports reflect the efforts of 44 industry representatives who formed the best practices working groups. Following literature reviews and consultation, they documented what they collectively recognized as services and strategies that produce positive health outcomes for individuals.

The Ministry of Health is grateful for the expertise and diligence these mental health consumers, family members and service providers brought to the work.

The reports on Best Practices for B.C.'s Mental Health Reform are:

- Housing
- Assertive Community Treatment
- Crisis Response/Emergency Services
- Inpatient/Outpatient Services
- Consumer Involvement and Initiatives
- Family Support and Involvement
- Psychosocial Rehabilitation and Recovery

**B.C.'s MENTAL HEALTH REFORM  
BEST PRACTICES FOR  
FAMILY SUPPORT AND INVOLVEMENT**

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**Important note**

The principles of psychosocial rehabilitation form the philosophical foundation for all best practices in mental health. These principles emphasize both consumer involvement in developing and realizing personal care and life goals and treatment and supports that help consumers manage their symptoms and build on their strengths.

## EXECUTIVE SUMMARY

Mental illness in the family creates a crisis that affects all members. The chronic stress family members experience in their new role as primary caregivers dealing with mental illness often undermines their own health, financial resources and ability to cope. This negative effect on the family unit can also hinder the stabilization and rehabilitation of the person with mental illness.

Training in coping skills, communication, information and support reduces the level of crisis in families, as well as reducing the relapse rate of the patient. In addition, the way families are treated and supported can contribute to the rehabilitation of the patient.

The 1993 report of the Task Force of Families of People with Mental Illness, *Families Sharing the Caring*, noted that unrealistic expectations were placed on family members, who were often expected to advocate and provide services that should be provided by the system. Confidentiality was cited as a frequent barrier to effective communication and support.

The task force recommendations form the basis for best practices in family support and involvement, which have been endorsed by family groups throughout the province. Best practices for family support and involvement include:

- *Provision of professional counselling for family members in need, including assistance in accessing services*—Case managers should provide family members with information, support and coping skills.
- *Partnerships among families, consumers and professionals in the treatment plan*—Families must be informed and aware of the treatment plan and discharge planning should focus not only on the individual's personal functioning, but also on the family's ability to care for the client.
- *Training opportunities and resources to support self-help*—Self-help models have great potential when skilled facilitators and resources are in place and family support groups are a cost-effective way to provide support to families who, in turn, can provide needed support and care to their mentally ill family member.
- *Diversified respite care*—Families have identified a strong need for flexible programs that will provide ongoing support through outreach, home care and activities for the family member who is ill.
- *Inclusion of families in the planning and evaluation of services*—Family members want opportunities for their voices to be heard and for input into planning and evaluation.

- *Expansion of training to mental health professionals to include skills and competencies that would increase their understanding and improve their ability to meet the needs of families*—A more comprehensive professional education program for mental health service providers will enhance support for families.
- *Increasing public awareness of mental health issues through education and a variety of approaches*—Better understanding and public awareness will reduce the stigma of mental illness, which increases the burden on family members.
- *A coordinated approach to providing family members with support, information, resources, education and training*—A designated position in each region will improve coordination between agencies, families and mental health services, and reduce families' difficulties in accessing services.

In order to implement best practices for family support and involvement, the partnership model, which allows the family voice to be heard by providing opportunities for input into planning and evaluating services, needs to continue and be enhanced.

The working group also recommends that a family and consumer forum occur twice a year for two days to review consumer and family issues that are systemic in nature. The forum could monitor implementation of the mental health plan using the best practices models.

**PART ONE:  
ELEMENTS OF BEST PRACTICE  
FOR FAMILY SUPPORT AND INVOLVEMENT**

**1. Introduction**

Mental illness in the family creates a crisis that affects all members. The impact is devastating and family members experience varying degrees of "bewilderment, fear, denial, rage, self-blame, pain, sorrow, empathic suffering and grief" (Lefley, 1987). The chronic stress family members experience in their new role as primary caregivers dealing with mental illness often undermines their own health, financial resources and ability to cope. This negative effect on the family unit can also hinder the stabilization and rehabilitation of the person with mental illness.

Research shows that the majority of people with mental illness are involved with their families. While any one professional may be involved with a client for a period of time, families are generally involved for a lifetime.

Studies have shown that training in coping skills, communication, information and support reduces the level of crisis in families, as well as reducing the relapse rate of the patient (Falloon, Boyd and McGill, 1984). Psychoeducational programs for families, which address a multidimensional perspective, have been shown to increase families' comfort in dealing with patients in the community and at home, lowering the relapse rate.

Studies also note that in addition to reducing the relapse rate, the way families are treated and the way they are supported can contribute to the rehabilitation of the patient (Spaniol, Zipple and Lockwood, 1992). An American study of 400 seriously ill patients estimated that family caregivers saved the government US\$4 million (Administration and Policy Mental Health, 1990).

However, confidentiality is often cited as a barrier to effective communication and support. Certain information about a patient can and should be shared with families who are in the caregiver role without violating clinical, legal or ethical principles (Pettila and Sadoff, 1992).

In 1992/93, the Adult Mental Health Division, British Columbia Ministry of Health, initiated a family task force that consulted with 550 family members and surveyed another 100. The report of the Task Force of Families of People with Mental Illness, *Families Sharing the Caring* (1993), noted that unrealistic expectations were placed on the family members. Families were often expected to advocate and provide services that should be provided by the system.

The report confirmed the needs of family members, which are well documented in the literature. Many families needed more help than mutual aid could offer. To achieve partnerships, it was noted that there needed to be a paradigm shift in the way professionals worked with families.

The task force report made recommendations that form the basis for best practices in family support and involvement, which have been endorsed by family groups throughout the province. Best practices for family support and involvement include:

- provision of professional counselling to family members in need, including assistance in accessing services
- partnerships among families, consumers and professionals in the treatment plan
- training opportunities and resources to support self-help
- diversified respite care
- inclusion of families in the planning and evaluation of services
- expansion of training to mental health professionals to include skills and competencies that would increase their understanding and improve their ability to meet the needs of families
- increasing public awareness of mental health issues through education and a variety of approaches
- a coordinated approach to providing family members with support, information, resources, education and training.

A partnership approach offers many benefits including mutual engagement and satisfaction, shared challenges and resources and enhanced treatment and rehabilitation (Lefley and Johnson, 1990). Over the past seven years, British Columbia has taken a leadership role in consumer and family initiatives and support by adopting the partnership philosophy and values, which include mutual respect, respect for different perspectives and experiences and the validity and acknowledgement of experiential knowledge (Bowles, 1989).

Evidence-based practice is limited in quality and quantity because the importance of family support and involvement has only recently been seen as legitimate.

Professionals should apply competency-based models to theory, research and practice concerned with families (Marsh, 1992 and Masterpasqua, 1989).

Improving the quality of life for people with mental illness requires commitment by the Ministry of Health and regional health authorities to a mental health system that provides supports for family members and promotes cooperation and communication among consumers, family members and professionals.

The partnership model allows the family voice to be heard by providing opportunities for input into planning and evaluating services. It is strongly recommended that this model continue. In order to implement best practices for family support and involvement, the partnership model needs to continue and be enhanced.

## **2. Access to Professional Counselling for Family Members**

After reviewing the Family Task Force report recommendations, the Ministry of Health, Provincial Family Mental Health Advisory Council identified professional counselling as the first priority. Many family members were paying for private counseling to cope with the effects that living with mental illness had on their own mental and physical health. This was an additional drain on their finances.

Case managers should be providing the family member(s) with information, support and coping skills. Some professionals see this as a priority; but others see this role as a conflict, especially around the areas of confidentiality. Other barriers are heavy caseloads and time constraints.

### **2.1 Recommendations**

1. Include family counselling in job descriptions for case managers.
2. Increase professionals' awareness of families' need for counselling.
3. Clarify or develop guidelines regarding confidentiality.
4. Identify family members' access to counselling.
5. Document family involvement.

### **2.2 Goal**

- To reduce the stress on family members, maintain the family unit and increase coping skills. (British studies have shown that crisis intervention/counselling for families has reduced relapses and rehospitalization of the ill member of the family.)

### **2.3 Evaluation**

- Through statistics and satisfaction forms, identify sources and availability of professional counselling.

### **3. Family/Consumer/Professional Partnerships in the Treatment Plan**

Confidentiality is often cited as a reason to exclude family members from the treatment plan. In many cases, the family is the primary caregiver. It is essential that they are informed and aware of the treatment plan. Discharge planning should focus not only on the individual's personal functioning, but also on the family's ability to care for the client.

#### **3.1 Recommendations**

6. Actively involve families in the treatment plan, the discharge plan and rehabilitation plan when appropriate.
7. Encourage the person with mental illness to see the benefits of including the family.
8. Solicit background information from families regarding history, medications, etc.
9. Orient families to the mental health system.
10. Provide education and information about confidentiality issue to professionals, consumers and family members.

#### **3.2 Goal**

- To improve the quality of care for the person with mental illness.

#### **3.3 Evaluation**

- The health authority has policies and guidelines in place that include families as partners in the treatment plan.
- Satisfaction surveys could be circulated to families and consumers.
- The health authority regularly offers training to mental health professionals that is designed to increase their skills and competencies in working with families.

### 3.4 References

Greater Vancouver Mental Health Society Family Task Group. (1998). *Putting the Family into the Picture: Communication, Cooperation and Collaboration in Care*. (Available from the Adult Mental Health Division, Ministry of Health.)

British Columbia Ministry of Health. (1989). *Releasing Personal Health Information to Third Parties*. Fact sheet. Freedom of Information and Protection of Privacy. (Available from the Adult Mental Health Division, Ministry of Health.)

## **4. Training for Self-Help**

The 1993 family task force report, *Families Sharing the Caring*, notes that peer support is often the only resource that family members have been able to access and the experience of other family members is seen as a great comfort to many.

Self-help models are highly recommended and have proved to have great potential if skilled facilitators and resources are in place. Studies show that family support groups are a cost-effective way to provide support to families who, in turn, can provide needed support and care to their mentally ill family member.

### **4.1 Recommendations**

11. Acknowledge the value of self-help as a legitimate means of support by providing training in peer support, facilitation and training skills.
12. Provide support for self-help groups with space and resources.
13. Coordinate self-help groups and provide resources for family to family outreach support.

### **4.2 Goal**

- To provide family members with emotional support and coping skills.

### **4.3 Evaluation**

- Provide a list identifying self-help groups or programs supported by the health authorities for families of persons with a mental illness.

### **4.4 Reference**

Directory of Family Education and Support Groups in Mental Health.  
(Available from the Adult Mental Health Division, Ministry of Health.)

## 5. Diversified Respite Care

Nationally, there are few respite program models for primary caregivers of someone with a mental illness. Traditional respite programs have not been readily accessible, and caregivers have identified the need for flexible programs that will provide ongoing support through outreach, home care and activities for the family member who is ill. A strong need has been identified for outreach to the family and for crisis housing as a form of respite.

### 5.1 Recommendations

14. Each region identifies the needs for respite care and provides a variety of options that meet those needs.

### 5.2 Goal

- To reduce the burden on primary caregivers.

### 5.3 Evaluation

- Document available services and respite needs, including utilization figures.

### 5.4 References

British Columbia Schizophrenia Society. *Respite Services for Family Caregivers of People with Mental Illness in British Columbia*. (1995). Vancouver, B.C.: B.C. Schizophrenia Society. (Available from the Adult Mental Health Division, Ministry of Health.)

## **6. Including Families in Planning and Evaluating Services**

Historically, the inclusion of families has been characterized by little consultation and no follow through. In 1992, the partnership model moved toward more meaningful involvement of families in planning evaluating services.

Because of stress and lack of available time, family members are often the most difficult to engage in participation on advisory committees. However, they want opportunities for their voices to be heard and for input into planning and evaluation. To prevent tokenism and selective representation, it is important to maintain the partnership model, which provides opportunities for the family perspective to be heard.

### **6.1 Recommendations**

15. Consult more widely, so all families have the opportunity for input.
16. Develop a variety of methods, so a broader representation of families has a voice.
17. Ensure that adequate forums and surveys are available for family members.
18. Improve communication and information sharing.
19. Provide training opportunities to facilitate the inclusion of families.
20. Provide a process to address concerns about services without fear of reprisal.

### **6.2 Goal**

- A partnership approach to planning and evaluation of services that acknowledges and respects the consumer and family perspective and experience.

### **6.3 Evaluation**

- Regional authorities provide documentation on their consultation process for involving families—including the number of family members involved in the consultation process and methods of inclusion.

## **7. Training Professionals to Understand the Needs of Families**

Family members state that an increase in training and sensitization to the effects of mental illness on families will promote greater understanding and facilitate a change in attitude. Support of families will be enhanced by a more comprehensive professional education program for mental health service providers.

### **7.1 Recommendations**

21. Include skills and competencies in working with families as part of the training provided for mental health professionals.
22. Provide ongoing, mandatory in-service training for working with families.
23. Provide sessions in education about partnership, where family members are included as presenters.
24. Provide training and information about Freedom of Information Guidelines regarding confidentiality.
25. Educate staff about the "Family Charter of Rights."

### **7.2 Goal**

- To promote a shift in attitude toward family members by mental health professionals.
- To recognize the value of including families.
- To sensitize professionals to the family's burden.

### **7.3 References**

Riverview Hospital. (1996). *Working With Families*. Education module. (Available from the Adult Mental Health Division, Ministry of Health.)

Provincial Mental Health Family Advisory Council, Adult Mental Health Division, Ministry of Health. *Guide for Families Working with Professionals: Building Partnerships in Mental Health*. (Available from the Adult Mental Health Division, Ministry of Health.)

Provincial Mental Health Family Advisory Council, Adult Mental Health Division, Ministry of Health. *Guide for Professionals Working with Families: Building Partnerships in Mental Health*. (Available from the Adult Mental Health Division, Ministry of Health.)

Information and Privacy Branch, Ministry of Health. (1998.) *Releasing Personal Health Information to Third Parties*. Fact Sheet: Freedom of Information and Protection of Privacy. (Available from the Adult Mental Health Division, Ministry of Health.)

Family Charter of Rights—see Appendix B.

## **8. Public Awareness and Education**

The stigma of mental illness is a major problem for family members and increases their burden. Better understanding and public awareness will reduce the stigma.

### **8.1 Recommendations**

26. Make ongoing regular presentations to schools, police, universities and workplaces in all regions.
27. Use the partnership education model (using the experiences of consumers and family members as teaching resources).
28. Encourage community participation in public awareness campaigns.
29. Coordinate regional public education programs.
30. Encourage community participation in national campaigns (e.g., Mental Health Week, Mental Illness Week).

### **8.2 Goal**

- To improve understanding of mental illness and the effects on the family.

### **8.3 Evaluation**

- Document educational events.

## **9. Regional Coordination of Family Support and Involvement**

Families need a more supportive environment when advocating for resources and support. The lack of coordination between agencies, families and mental health services makes accessing services a constant frustration. Resources and information should be made available for families on all best practice recommendations, through a designated position in the region.

### **9.1 Recommendation**

31. Have a designated person at management level to facilitate partnerships and represent consumers and families.

### **9.2 Goal**

- An improved mental health system.

### **9.3 Evaluation**

- Provincial standards and accreditation should include an expectation that training for professionals on working as partners with families and consumers will be provided.
- Job descriptions will reflect competencies required for working with families.
- There will be provincial standards and written policy regarding procedures in the regions for working with families (e.g., counselling).

## 10. Provincial Networking Proposal

The Family Support and Involvement Best Practices Working Group has been asked to recommend how family members, in a regionalized model of health care delivery, can continue to network inter-regionally and maintain a provincial perspective. However, we strongly suggest that a broader-based consultation with consumers and family members needs to occur before a final decision is reached.

The following recommendation was supported in principle by the Provincial Mental Health Family Advisory Council at their March 24, 1999 meeting.

### 10.1 Recommendation

32. We recommend a family and consumer forum occur twice a year for two days:

- day one would be a separate meeting of family member representatives from all health regions
- day two would be a *joint meeting* with consumer representatives from all health regions, the Mental Health Advocate and the Provincial Mental Health Advisory Council, with attendance by the Minister of Health and Minister Responsible for Seniors at one joint meeting each year.

A small working group of consumers and family members along with rotating representation from mental health managers would have responsibility for organizing the forums, which would be held in various British Columbia communities. The forums would review consumer and family issues that are systemic in nature and could monitor implementation of the mental health plan using the best practices models.

## 11. Summary of Recommendations

1. Include family counselling in job descriptions for case managers.
2. Increase professionals' awareness of families' need for counselling.
3. Clarify or develop guidelines regarding confidentiality.
4. Identify family members' access to counselling.
5. Document family involvement.
6. Actively involve families in the treatment plan, the discharge plan and rehabilitation plan when appropriate.
7. Encourage the person with mental illness to see the benefits of including the family.
8. Solicit background information from families regarding history, medications, etc.
9. Orient families to the mental health system.
10. Provide education and information about confidentiality issue to professionals, consumers and family members.
11. Acknowledge the value of self-help as a legitimate means of support by providing training in peer support, facilitation and training skills.
12. Provide support for self-help groups with space and resources.
13. Coordinate self-help groups and provide resources for family to family outreach support.
14. Each region identifies the needs for respite care and provides a variety of options that meet those needs.
15. Consult more widely, so all families have the opportunity for input.
16. Develop a variety of methods, so a broader representation of families has a voice.
17. Ensure that adequate forums and surveys are available for family members.
18. Improve communication and information sharing.

19. Provide training opportunities to facilitate the inclusion of families.
20. Provide a process to address concerns about services without fear of reprisal.
21. Include skills and competencies in working with families as part of the training provided for mental health professionals.
22. Provide ongoing, mandatory in-service training for working with families.
23. Provide sessions in education about partnership, where family members are included as presenters.
24. Provide training and information about Freedom of Information Guidelines regarding confidentiality.
25. Educate staff about the “Family Charter of Rights.”
26. Make ongoing regular presentations to schools, police, universities and workplaces in all regions.
27. Use the partnership education model (using the experiences of consumers and family members as teaching resources).
28. Encourage community participation in public awareness campaigns.
29. Coordinate regional public education programs.
30. Encourage community participation in national campaigns (e.g., Mental Health Week, Mental Illness Week).
31. Have a designated person at management level to facilitate partnerships and represent consumers and families.
32. We recommend a family and consumer forum occur twice a year for two days:
  - day one would be a separate meeting of family member representatives from all health regions
  - day two would be a *joint meeting* with consumer representatives from all health regions, the mental health advocate and the Provincial Mental Health Advisory Council, with attendance by the Minister of Health and Minister Responsible for Seniors at one joint meeting each year.

A small working group of consumers and family members along with rotating representation from mental health managers would have responsibility for organizing the forums, which would be held in various British Columbia communities. The forums would review consumer and family issues that are systemic in nature and could monitor implementation of the mental health plan using the best practices models.

## PART TWO: APPENDICES

### Appendix A: Responses from the Forum on Provincial Best Practices in Mental Health

Summarized here are the 29 responses received at the November 4 to 5, 1999 forum on provincial best practices in mental health.

**1. What do you like about the best practices report and its recommendations, and why?**

- I felt the draft covered their topic well. I hope this is the “true” start of “best” practices in mental illness!!
- Happy to see that family members and consumers are not treated as adversaries.
- The training of mental health professionals is also most important in order for them to realize that in many cases the family is in a key position to influence the outcomes of the treatment.
- Excellent document.
- Good recommendations.
- Articulates value of family partnerships.
- I feel that the principles expressed in this document are representative of the 1992 report, *Families Sharing the Caring*. I endorse them fully.
- The need for counselling of family members has been assessed and never addressed. Hopefully funding will accompany this.
- Thorough.
- Accurate.
- The recommendations are good and an excellent starting point to assure better care for families and the ill person.
- Wonderful structure to paper.
- Great examples to support points, integration of general principles and specific methods of operation.
- Clear and all encompassing recommendations.
- Feel the discussion guide is very effective.

- Very much agree.
- Common sense approach.
- Case studies.
- Provide insight into what families/consumers require in terms of education/support/involvement with the mental health system.
- Information to assist professionals in providing an improved services to families/consumers.
- Inclusion of case to illustrate your position—this brings the document into reality. I liked that very much!
- A very good overview as a document.
- Like the case studies, as I find they express well the issues faced by families.
- Support the breadth of recommendations.
- Excellent recommendations regarding professional standards and skills needed to address family issues.
- I liked the initial premise that treatment is most effective in cultures where families are part or even foremost in that practice. The draft report follows this theme throughout. As a family member, and family to family instructor, I am especially close to the effectiveness of family involvement.
- It has always been there, but best practices is to have *this* thoughtful report.
- The report was excellent in outlining the concerns of families and illustrating (sometimes by examples of failures) of the roles that families should play in the care of the mentally ill person. I thought the case studies were particularly effective.
- Good paper.
- Confidentiality—there has to be a way to share information in order to approach treatment in the most informative way.
- Involving the family because they have the best chance of having the right knowledge.
- Public awareness—in order for things to changes in government, the whole general public must be educated and informed.
- Including education of families in the institutional/professional environment.
- Defining confidentiality—not a problem when a patient is certified but a major hindrance on volunteer admission.
- Perhaps family needs to be formally identified as part of the core “team” in which case confidentiality is not an issue.
- Inclusiveness.

- Precise.
- Broad as well.

**2. Do you disagree with any of the features of the report? If so, why?**

- Need to be more emphatic.
- How this document will integrate with the other (six) documents? In my view, family issues ought to deal with explicitly in each document.
- Believe a stronger language could be used—i.e., recommend policy statements to providers.
- Documents should be amended to reflect the feedback. Feedback information must be included/integrated into the document to be meaningful.
- Too “disease” oriented—i.e. chronic care, et al. Where is prevention? We are too vented in care and not oriented toward prevention and early identification.
- Too what is oriented not enough what can /should be?
- Needs stronger language articulating “best practices” vs “recommendations”.
- There needs to be a more assertive position taken in the recommendations.
- More specific in the needs.
- Education is different than training and needs to be clarified.

**3. Are there any areas you would have wanted included that have been missed? Please identify.**

- Treat deserving families with dignity and respect. The family must also try to be gracious, which when your loved one is in crisis, is difficult.
- Formalize the connections between mental health units for tracking people and assisting with getting people support in other communities.
- Mention of families/friends of persons with short-term mental health problems. This is often a recurrent illness (e.g., depression) that impacts families a lot. Yet the stigma leads people to deny status and stay hidden so they usually don’t get involved in lobbying/advocacy.
- Need a standard comment for release of information (to be signed by consumer) that can be used regionally.
- Training of general practitioners, FAWs housing, clergy and any other groups that work with families and consumers on a provincial basis. This training is dynamic (always occurs and changes).

- Need for advocacy on behalf of family members.
- The use of stronger language and more *assertive* (not aggressive) in the approach of this document.
- Question: Are these principles fundable as programs?
- One aspect is very important: respect, respect, respect, respect!
- Address doctors' negligence.
- Medical schools are negligent with mental illness: The brain is a part of the body requiring medical attention.
- The health of the family is a medical matter.
- Ways to access family education opportunities in rural areas (e.g. community services could be more helpful).
- Early psychosis identification and intervention (EPII).
- Prevention.
- Reference clinical research and best practices regarding EPII: clearly a clinical role for families as standard practice.
- Define respite and crisis housing more clearly in document.
- Just use stronger words. Emphasize! Respect!
- Include training of mental health professionals during their training—*part of college curriculum* for MDs, RNs/RPNs, social workers, etc. Is required—i.e., family to family and bridges. See reference to family to family, bridges programs in #1.
- The family is an integral part of the system for treatment and recovery of the ill person. The formal education of professionals must include working with families and the benefits derived.
- A major emphasis must be put on families and professionals cooperating.
- More specific information on some of the recommendations—i.e. respite care.
- Recommend inclusion of contact numbers for families in the clinical information systems, with attempt to gain permission of consumer when well.
- Recommend accountability recommendation of performance indicator for inclusion of families.
- Respite care for families needing to be included with guidelines this document—I like the notion of in home care as you described.
- I think there is a need to include in the document information/phone numbers/tips to assist the networking between regions to find transient family members. It would be useful for professionals to provide a better service to families.
- Please add: specific education led by families regarding advocacy, guardianship,

- *Mental Health Act.*
- Does the respite service (to be feasible/economical) have some guidelines regarding resources to those families with someone with serious mental illness first? (\*not just to those who know how to work the system)
- Access issue to help family members.
- Page 9 presentations to schools, universities, police et al (standard) presentations educate ER physicians.
- Get the mental health emergency system/support line phone number at the front of the telephone book right next to 911.
- Ethics—we get caught up in legalities—ethics has helped me to deal with issues of rights, etc.
- Integration with social services—culturally safe care.
- Add to body of document—geriatric and early intervention.
- Would like to have a specific recommendation on best practices in providing support to older adults who have mental illness and co-existing physical illness. An example could be that: All staff providing mental health services include outreach, family counselling as part of their core services.
- Support and counselling about bereavement and end of life issues be included in the core education of mental health staff.
- All mental health staff have education about the psychological, physical and social changes that occur as a result of the aging process.
- That peer counsellors be an integrated part of all geriatric mental health programs.
- Clear and concise.
- More stress on current educational programs.
- Case studies help put concepts in perspective.
- Continuum of existing peer support program.
- It is essential part of best practices because peer's support is the most effective way of prevention and supportive continuum care for consumers of mental health. They are the experts of needs here.
- Only suggestion would be to include or identify examples of programs in some areas of bc that are actually working—i.e., family to family, kids in control, partnership education, etc.

### **Comments from the BC Psychogeriatric Association**

This report focuses entirely on family support for families of mentally ill younger adults. Some of the principles and recommendations are generic enough to apply to families of the elderly, but the specific needs of this second group are not mentioned. While the families of young adults generally consist primarily of parents and siblings, families of the elderly with mental health problems may be spouses who are also elderly or children who could also be old or who could have young families that also require their attention. The issues and decisions faced by families of the elderly are therefore very different from those faced by families of younger adults.

Appended to the report is a model of a training program for professionals working with families. The case study example is a parent-child situation in which it is the child who becomes mentally ill. The assumption is that, using a psychosocial rehabilitation model, both child and parents will receive appropriate support and assistance as they understand the nature of the mental illness and learn appropriate coping strategies. The trajectory of the mental illness is different and the expectations of the families are consequently altered in the direction of hoping for increasing independence and eventual recovery. The reverse is generally the case for the families of the elderly whose trajectory is more likely to be one of increasing dependence with a final decline to death. The kinds of information, support and assistance required by the families of the young adult and the elder are therefore rather different.

Nevertheless, most of the basic recommendations of the report still stand with respect to the elderly:

- professional counselling to family members and help in accessing services
- inclusion of family members in treatment planning
- respite care
- inclusion in the planning and evaluation of services
- training for mental health professionals to improve their abilities to meet the needs of families.

A strategic plan for mental health services for the elderly that would focus on the particular needs of the elderly and their families would better address the issues of concern to that population group. Support for family members of the elderly could then be discussed with focused reference to the particular needs of those families.

## **Appendix B: Family Charter of Rights**

Developed by the Provincial Mental Health Family Advisory Council, Adult Mental Health Division, Ministry of Health.

### **Families have a right:**

- **To explicit information that families do not cause mental illness.**
- **To basic information about diagnosis, treatment, plan options and prognosis.**
- **To information about behavior management, advice and guidance about resources in the community and the availability of peer support.**
- **To education that would assist in coping with mental illness.**
- **To respect from professionals for the expertise of the family, as well as the sharing of power in the therapeutic process.**
- **To become appropriately assertive and to overcome traditional socialization that teaches families not to question authority.**
- **To be involved with their family member as a support system and resource.**
- **To have a social ethic that is more concerned about the welfare of the person with mental illness, rather than cost effectiveness.**
- **To a mandated role on governance or advisory boards and a voice in mental health planning that directly affects their lives.**
- **To a non-adversarial legal system that is understanding to potential tragedy and helpful in attempts to prevent disaster from occurring.**

## GLOSSARY

**accountability.** The management team is responsible for defining expected outcomes and performance measures, a plan for monitoring service delivery and activity reporting structure. The Ministry of Health is responsible for the expenditure of public funds.

**accreditation.** External, formal review of an agency's performance and adherence to standards of delivering care services. Certification by a national organization whose business is the evaluation of compliance by service organizations (such as hospitals) with pre-set standards of care and/or service.

**acute care** (also referred to as secondary level care). Diagnostic and therapeutic health care (in medical disciplines, including psychiatry) provided by health care professionals, usually in a hospital setting and for a short duration.

**acute psychiatry (inpatient).** Assessment, diagnosis, treatment, stabilization and short-term rehabilitation of people with serious mental illnesses admitted voluntarily or involuntarily to a hospital psychiatric unit, which often entails emergency psychiatric care.

**adult.** Person 19 years of age or older.

**advocacy.** The act of informing and supporting people so they can make the best decisions possible for themselves, or an act or acts undertaken on behalf of others when they are unable to act on their own.

**ALOS.** Average length of stay.

**Assertive Community Treatment (ACT).** An alternative to other forms of community care which, because of its comparative expense, should be targeted to the most appropriate clients (i.e., frequent users of the system, including inpatient care and forensic services). The 1998 mental health plan addresses the two per cent of the population with serious and persistent mental illness, with accompanying functional disabilities. The plan supports intensive or assertive community treatment for only a portion of the most seriously mentally ill, up to 8,200 clients.

**best practices in mental health.** Descriptions of what can be done to facilitate change for the better in mental health policies, practices and initiatives. Factors that facilitate change include clearly articulated conceptual bases, wide stakeholder involvement, political vision and will, infrastructure supports, the reallocation of funds and personnel from institutions to community, partnerships beyond health, reduction in stigma, enthusiastic leaders, skilled staff and the Canadian Mental Health Association National Framework for Support.

**biopsychosocial approach/model.** Services that take into account the biological, psychological and social needs of an individual. Involves multidisciplinary care teams, including physicians, nurses, pharmacists, social workers, occupational therapists, dietitians and psychologists.

**case management.** The coordination of a consumer's health care, housing, employment, training and/or rehabilitation services, usually by one person (the case manager) operating in a team environment who liaises with all others providing services to the consumer. Case management provides active outreach, coordination of personalized care plans and monitoring of mental health status.

**clinical practices guidelines.** Systematically developed statements to assist practitioners in decisions about appropriate health care for clients in specific clinical circumstances.

**community resource base concept.** This concept "assumes the perspective of the person in the centre: the consumer who is actually living and coping with a mental health problem. The majority of consumers now live most of their lives in the community and are influenced by a wide range of factors. These factors include housing, education, work, income, mental health services, consumer groups and organizations, family and friends and generic community services and groups.

**consumers.** People who use mental health services.

**crisis stabilization program.** Provides community-based, short-term treatment and stabilization services for individuals in psycho social and psychiatric crises as an alternative to hospitalization. During the client's stay, a thorough assessment is completed, intensive brief crisis intervention services are provided and an immediate action plan for community re-integration is implemented.

**decompensate.** The psychotic symptoms return or the person's ability to function is disrupted.

**designated facility.** A hospital or provincial mental health facility that may admit involuntary patients under the *Mental Health Act*.

**determinants of health.** Factors that influence and determine health status. These include social, economic and physical environments, health services, biological influences and health behaviors and skills.

**DSM-IV.** *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition.* The American Psychiatric Association's classification tool to assist care practitioners in classifying mental disorders based on symptoms.

**dual diagnoses.** Commonly used to describe the condition of people who have a mental illness and either a mental handicap or substance misuse issues.

**ECT.** Electroconvulsive therapy.

**emergency accommodation.** Facilities that offer short-term emergency accommodation in a supportive environment for people with marked behavioral and social problems associated with mental illness who have no other immediate housing options available to them, but who do not require care in a hospital or intensively staffed facility.

**empowerment.** The capacity of choice. Includes the ability to define, analyze and act on problems one experiences in relation to others and in one's environmental living conditions. As a process, describes the means through which internal feelings of powerlessness are transformed and group actions initiated to change the conditions that create or reinforce inequalities in power.

**epidemiology.** Prevalence of a disease in a particular community at a particular time.

**etiology.** Pertaining to the science of the causes of disease.

**evidence-based decision making.** A process that takes facts, data and evidence into account. It is an essential part of effective and accountable planning, action and evaluation.

**family care home.** Care provided in approved homes to one or two adults with a serious and persistent mental illness who are unable to live independently. This category of care is not subject to licensing under the provincial *Community Care Facilities Act*.

**forensic.** Forensic Psychiatric Services provides assessment, diagnosis, treatment, detention and supervision of people with mental illness who are involved with the criminal justice system.

**FTE (full-time equivalent).** FTE is the unit used to describe a full-time position. For example, two half-time positions equal one FTE.

**functional impairment.** An individual's reduced ability to perform usual daily activities. A number of measurements exist to gauge a person's level of functioning (and level of functional impairment). The global assessment of functioning (an aspect of assessment that is part of the ASP *DSM-IV*) is one such tool.

**governance.** The authority to operate a health care program. Governing bodies, such as boards of directors or trustees, generally define the vision, mission and values of an organization and set goals, objectives and priorities for its operation.

**guidelines.** A suggestion or set of suggestions that guides or directs action. The purpose of a guideline is to provide additional information that assists service providers to comply with policy. Guidelines may be suggestions on how to carry out or implement policy. Whereas health authorities and services providers must comply with Ministry policy, they do not have to comply with guidelines.

**health authorities.** Public bodies mandated under the *Health Authorities Act* to govern, manage and deliver health services in a defined geographic area. Refers to either Regional Health Boards (RHBs) or Community Health Councils (CHCs). Community Health Service Societies (CHSSs) are included here, although they do not have status under the act and derive their authority from their constitution and bylaws, established pursuant to the *Society Act*.

RHBs govern the delivery of all health services within a designated region.

CHCs govern the delivery of acute and continuing care-based services, such as hospitals and intermediate-care facilities, in areas of the province where there are no RHBs.

CHSSs govern the delivery of services that are broadly regional in nature—public health, community health care nursing, community rehabilitation, case management, health services for community living and adult mental health services—in areas of the province where there are no RHBs. Collectively, the CHSSs and the CHCs within a region govern the delivery of all health services in the region.

**health status.** A group or community's status of health evaluated by means of universal epidemiological indicators, such as the rates of illness and death, life expectancy and potential years of life lost, and compared with other populations.

**integration.** Organization of service entities along a continuum, ranging from cooperation between agencies to full amalgamation of governance, management and service delivery structures, in order to ensure that the client's needs are met in a coherent, unified, holistic and efficient manner.

**mandate.** The scope of an organization's responsibility.

**Mental Health Act.** British Columbia's *Mental Health Act* was proclaimed in 1964.

Its purpose is to ensure "...the treatment of the mentally disordered who need protection and care..." The main focus of the *Mental Health Act* is to provide authority, criteria and procedures for involuntary admission and treatment. The act also provides protection to ensure that these provisions are applied in an appropriate and lawful manner.

**mental health crisis.** An acute disturbance of thinking, mood, behavior or social relationship that requires an immediate intervention, which involves an element of unpredictability that is usually accompanied by a lack of response to social controls and may be defined as such by the client, the family, or other members of the community, including family physicians or police.

**multiaxial assessment.** An assessment on several axes, each of which refers to a different domain of information that may help the clinician plan treatment and predict the outcome. There are five axes included in *DSM-IV*:

Axis I Clinical Disorders

Axis II Personality Disorders

Axis III General Medical Conditions

Axis IV Psychosocial and Environmental Problems

Axis V Global Assessment of Functioning

**operating budget.** The amount of funding necessary to pay for the cost of running an organization.

**organic brain syndrome.** A psychological or behavioral abnormality associated with a temporary or permanent dysfunction of the brain caused by disease processes, strokes or accidents.

**outreach.** Services are taken to the consumer (e.g., at home, at work, in a facility) rather than requiring the consumer to attend a clinic or hospital.

**partnership model in mental health.** Services provided through individual care planning carried out in a partnership among, the Ministry of Health, service providers, local governments, family members, other unpaid caregivers and consumers, to meet the needs of consumers, in the context of all the roles and functions of all parts of the mental health system.

**psychosocial rehabilitation.** Psychiatric rehabilitation services designed to assist a person with a serious mental illness in effectively managing the illness and compensating for the functional deficits associated with the illness. People who receive psychosocial rehabilitation services are significantly more likely to be able to return to work or school or to resume a participating role in the community. The range of psychosocial services may include rehabilitation, case management, residential treatment and support, crisis services, social services, housing, vocational rehabilitation, substance abuse treatment, peer support and family support.

**psychotropic drug.** Any medication that has a primary effect on the central nervous system with the intention of improving moods or thinking. The term “typical” psychotropic drug refers to relatively old products. The term “atypical” refers to psychotropic drugs that are relatively new and designed to treat a wider range of symptoms with fewer side effects.

**primary care.** Preventive, diagnostic and therapeutic health care provided by general practitioners and other health care professionals. The first level of care normally accessed by clients and patients. Primary care may include referral to more specialized levels of care, e.g., secondary (hospital or specialist care). Family doctors are often referred to as “primary care physicians.”

**quality assurance (QA).** An ongoing program to ensure that standards of service delivery are being met.

**residential care.** Provided in community-based, licensed facilities that are staffed to provide full-time care, supervision and psychosocial rehabilitation for people whose social and/or mental functioning prevents them from living more independently. These facilities average 13 residents and are regulated by the *Community Care Facility Act* and the Adult Care Regulations. The facilities are subject to program standards, guidelines, policies and procedures.

**residential care for specialized needs.** Augmented resources provided to community care settings, to respond to the complex care needs of people with severe neuro-psychiatric disorders and very challenging behaviors.

**residential program/services.** An organized program enabling clients to have the best possible quality of life, while remaining or becoming integrated into the community. Residential services may be provided in rural or urban areas, in houses, apartments, townhouses or other culturally appropriate settings.

**respite.** Temporary, short-term care, designed to give relief or support to a family caregiver who has responsibility for the ongoing care and supervision of a family member with a serious mental illness. Respite can be provided inside or outside the home.

**secondary level care.** (See *acute care*)

**serious mental illness.** Generally, illnesses such as schizophrenia, manic depression and bipolar disorder represent the most serious mental illness. It is acknowledged, however, that there are others for whom medical risk and level of impairment—regardless of diagnosis—defines their mental illness as “serious.”

**stakeholders.** Representatives of the British Columbia mental health care community of interest (e.g., consumers, families, professionals, unions, health authorities).

**standard.** An established, measurable, achievable and understandable statement that describes a desired level of performance against which actual performance can be compared. Used by service providers to attain and maintain quality of care or service delivery, they state what consumers and the public can expect from a service. While a policy tells service providers what to do, a standard is a tool that allows a service provider to measure, monitor and compare actual performance against a benchmark.

**supported education.** An effective means of helping individuals with psychiatric disabilities to achieve success in accessing and pursuing educational opportunities of their choice.

**supported housing.** A variety of living arrangements (usually self-contained living units) for people with a serious and persistent mental illness who are able to live independently with the assistance of a range of support services and the provision of a housing subsidy.

**tertiary care.** The care of people with serious, complex and/or rare mental disorders who, by reason of severe psychotic behavior or the need for specialized staff or facilities, cannot be managed by the resources available at the primary and secondary levels of care in the province. It also includes specialized services such as child and adolescent, psychogeriatric, alcohol/substance abuse and forensic mental health services.

Tertiary mental health care includes specialized intensive acute-care assessment and short-term treatment programs and both short-term (episodic) and long-term institutional care for severe chronic cases. It excludes long-term care that does not require daily access to the special clinical resources that are available only within the tertiary care programs.

**utilization data.** The information required to compare observed use of resources with recognized standards for use.

**utilization management.** Process by which agencies decide on the efficient use of care resources, comparing the observed use of resources with recognized standards of appropriate, timely and cost-effective utilization. The objective is to ensure that the right services are provided to the intended consumers, when they most need them, at the lowest cost consistent with high-quality care.

**values.** The beliefs of an organization that underlie its principles and actions and form the basis for planning and operating services.



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