

Appendix A

Support Needs of Individuals With Severe and Persistent Mental Illness on Prince Edward Island

• Research Tools •

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8. In dealing with people who have a serious and persistent mental illness, how would you rate the following:

	Poor			Excellent		n/a
a. Access to Psychiatrist	1	2	3	4	5	[]
b. Acute Services/Psychiatric Beds	1	2	3	4	5	[]
c. Awareness of Services	1	2	3	4	5	[]
d. Counselling/Therapy	1	2	3	4	5	[]
e. Day Programs	1	2	3	4	5	[]
f. Dental	1	2	3	4	5	[]
g. Education	1	2	3	4	5	[]
h. Employment	1	2	3	4	5	[]
i. Financial Support	1	2	3	4	5	[]
j. Home Care	1	2	3	4	5	[]
k. Housing	1	2	3	4	5	[]
l. Medications	1	2	3	4	5	[]
m. Self Help Groups	1	2	3	4	5	[]
n. Social Activities	1	2	3	4	5	[]
o. Substance Use/Abuse Counselling	1	2	3	4	5	[]
p. Transportation	1	2	3	4	5	[]
q. Other (please specify below)						[]

9. Please list the three areas from Question 8 that you feel require the most attention.

- 1) _____
- 2) _____
- 3) _____

10. What are the problems you encounter when trying to deliver services, supports and programs to people with serious and persistent mental illness?

11. What *works well* when delivering services, supports, and programs to people with serious and persistent mental illness?

12. What *would help you* deliver services, supports, or programs more effectively to people with a serious and persistent mental illness?

13. Additional Comments:

Thank you for taking the time to complete this survey. If you have any questions, contact Dave Stewart at the Canadian Mental Health Association (902) 628-3656. Please return your survey **no later than October 31, 2003**, using the Self Addressed Stamped Envelope provided, to:

**Service Provider Survey
Canadian Mental Health Association - PEI Division
P.O. Box 785
Charlottetown, PE C1A 7L9**

- General Practitioner Survey -

Support Needs for People With a Serious & Persistent Mental Illness

1. **What area of the province do you serve?**

Prince Kings Queens Province-wide

2. **Approximately how many people with serious and persistent mental illness do you currently serve?**

1-10 11-25 26-50 51-99 100 to _____

3. **In addition to the service you provide, please list other supports, services, and programs to which you refer people with a serious and persistent mental illness.**

4. **In dealing with people who have a serious and persistent mental illness, how would you rate the following? Also, please circle the three areas that you feel require the most attention.**

	Poor				Excellent	n/a
a. Access to Psychiatrist	1	2	3	4	5	[]
b. Acute Services/Psychiatric Beds	1	2	3	4	5	[]
c. Awareness of Services	1	2	3	4	5	[]
d. Counselling/Therapy	1	2	3	4	5	[]
e. Day Programs	1	2	3	4	5	[]
f. Dental	1	2	3	4	5	[]
g. Education	1	2	3	4	5	[]
h. Employment	1	2	3	4	5	[]
i. Financial Support	1	2	3	4	5	[]
j. Home Care	1	2	3	4	5	[]
k. Housing	1	2	3	4	5	[]
l. Medications	1	2	3	4	5	[]
m. Self Help Groups	1	2	3	4	5	[]
n. Social Activities	1	2	3	4	5	[]
o. Substance Use/Abuse Counselling	1	2	3	4	5	[]
p. Transportation	1	2	3	4	5	[]
q. Other (please specify below)						[]

5. What would help you deliver services, supports, or programs more effectively to people with a serious and persistent mental illness?

6. Additional Comments:

Thank you for taking the time to complete this survey. If you have any questions, please contact Dave Stewart at the Canadian Mental Health Association (902) 628-3656. Please return your survey **no later than October 31, 2003**, using the Self Addressed Stamped Envelope provided, to:

**General Practitioner Survey
Canadian Mental Health Association - PEI Division
P.O. Box 785
Charlottetown, PE C1A 7L9**



Canadian Mental Health Association
Prince Edward Island Division

Call for Written Submissions

If you or someone in your family has a serious and persistent mental illness (such as schizophrenia or bipolar disorder), the Canadian Mental Health Association-PEI Division would like to hear from you regarding your experience with mental health services on P.E.I. The information gathered will be used for research to help identify mental health support needs in the province. Quotes from submissions also may be used in our final report, but these will remain anonymous.

Please send your comments (no longer than two pages) by **October 24, 2003**, to:

Support Needs Comments
CMHA-PEI Division
Box 785
Charlottetown, PE C1A 7L9





Sample Covering Letter #1

DEAR SERVICE PROVIDER:

We need your input ...

The Canadian Mental Health Association-PEI Division, in partnership with the Department of Health and Social Services, is conducting research to identify Mental Health Support Needs **across the Island**. In short, we are developing a picture of the current state of mental health care on P.E.I. by finding out what's working, what's not working, and what additional supports are needed. Consumers and Family Members will be a part of the process, but we also need to hear from the people who address these issues on a daily basis, namely you.

If you are a Service Provider who works with people aged 18-60, who have a Serious and Persistent Mental Illness (see definition below), please take a few moments to complete the survey that has been attached. It has been designed to obtain the necessary information in the shortest time possible, approximately 15 minutes.

Serious & Persistent Mental Illness (Definition)

Serious and Persistent Mental Illness (SPMI) is defined by: 1) the effect of the illness on daily life, 2) the duration of the illness and 3) the diagnosis.

Effect: The illness interferes with the ability to perform basic life skills and to function in social settings.

Duration of Illness: The illness is on-going in nature, although there may be periods of mental wellness.

Diagnosis: SPMI includes diagnosable disorders such as schizophrenia, mood disorders, paranoia and other psychoses, and severe personality disorder. A person with SPMI may be diagnosed as having more than one disorder.

The confidentiality of all participants will be respected as names are not required and individuals will not be identified. Anonymous quotes may be used in the final report, but the interest of the report lies only in your experience.

Please return the completed survey using the enclosed Self Addressed Stamped Envelope no later than October 31, 2003. If you have any questions about this survey or the project, please contact me at (902) 628-3656. Thank you for taking the time to complete this survey. In so doing you have made an invaluable contribution to the Support Needs Project.

Sincerely,

David Stewart
Project Coordinator





Sample Covering Letter #2

DEAR GENERAL PRACTITIONER:

Family Physicians are often the first point of contact for people with mental illness.

The Canadian Mental Health Association-PEI Division, in partnership with the Department of Health and Social Services, is conducting research to identify Mental Health Support Needs **across the Island**. In short, we are developing a picture of the current state of mental health care on P.E.I. by finding out what's working, what's not working, and what additional supports are needed. Consumers, Family Members, and Service Providers are involved in the research, but GP's are also an important part of the process and we need to hear from you.

If you have provided service to people aged 18-60, who have a Serious and Persistent Mental Illness (see definition below), please take a few moments to complete the survey that has been attached. This is a separate condensed survey that has been created for GP's. It has been designed to obtain the necessary information in the shortest time possible, approximately 10 minutes.

Serious & Persistent Mental Illness (Definition)

Serious and Persistent Mental Illness (SPMI) is defined by: 1) the effect of the illness on daily life, 2) the duration of the illness and 3) the diagnosis.

Effect: The illness interferes with the ability to perform basic life skills and to function in social settings.

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The confidentiality of all participants will be respected as names are not required and individuals will not be identified. Anonymous quotes may be used in the final report, but the interest of the report lies only in your experience.

Please return the completed survey using the enclosed Self Addressed Stamped Envelope no later than October 31, 2003. If you have any questions about this survey or the project, please contact me at (902) 628-3656. Thank you for taking the time to complete this survey. In so doing you have made an invaluable contribution to the Support Needs Project.

Sincerely,

David Stewart
Project Coordinator





Sample Covering Letter #3

DEAR PSYCHIATRIST:

The Canadian Mental Health Association-PEI Division, in partnership with the Department of Health and Social Services, is conducting research to identify Mental Health Support Needs **across the Island**. In short, we are developing a picture of the current state of mental health care on P.E.I. by finding out what's working, what's not working, and what additional supports are needed. Consumers, Family Members, GP's and Service Providers are involved in the research, but psychiatrists are a very important part of the process and we need to hear from you.

If you have provided service to people aged 18-60, who have a Serious and Persistent Mental Illness (see definition below), please take a few moments to complete the survey that has been attached. This is a separate condensed survey that has been created for psychiatrists. It has been designed to obtain the necessary information in the shortest time possible, approximately 10 minutes.

Serious & Persistent Mental Illness (Definition)

Serious and Persistent Mental Illness (SPMI) is defined by: 1) the effect of the illness on daily life, 2) the duration of the illness and 3) the diagnosis.

Effect: The illness interferes with the ability to perform basic life skills and to function in social settings.

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The confidentiality of all participants will be respected as names are not required and individuals will not be identified. Anonymous quotes may be used in the final report, but the interest of the report lies only in your experience.

Please return the completed survey using the enclosed Self Addressed Stamped Envelope no later than October 31, 2003. If you have any questions about this survey or the project, please contact me at (902) 628-3656. Thank you for taking the time to complete this survey. In so doing you have made an invaluable contribution to the Support Needs Project.

Sincerely,

David Stewart
Project Coordinator



FOCUS GROUP QUESTIONS

- 1. Where can you go for help with your mental illness?**
- 2. Tell us about your personal experiences with these services and supports.**
- 3. Describe the problems faced in trying to become or remain well.**
- 4. What would help you with the problems you face?**



Sample

Focus Group Permission Form

I, _____, agree to participate in the consumer focus group co-ordinated by The Canadian Mental Health Association - PEI Division on Monday, November 3, 2003, from 3:00 pm to 5:00 pm at the Breakwater Wellness Centre.

I am aware that the purpose of the focus group is to get the opinions of consumers about Mental Health Services on Prince Edward Island, and that these opinions will be included in a report to the Department of Health and Social Services.

I am aware that notes will be taken during the session for research only. I understand that my name will not appear in the written report.

Signature _____

Date _____

Appendix B

Support Needs of Individuals With Severe and Persistent Mental Illness on Prince Edward Island

• Summary of Identified Support Needs •

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9. General Education Needs (28).....	p. 4
10. Dental Care Needs (29).....	p. 4

#	SUMMARY – IDENTIFIED SUPPORT NEEDS	Report Reference
1.	It was identified by participants from all sectors that there is a need to have standardized philosophy and protocols which provide for, and expect, communication and collaboration amongst mental health services and providers across P.E.I. As a result, the services and information provided will be consistent, responsive and accessible. This practice was most evident in Queens Region.	Service - Quality: Page 15
2.	It was identified by participants from all regions that psychiatric units on Prince Edward Island, particularly Prince County Psychiatric Unit and Hillsborough Hospital, are lacking in formalized group sessions and other unit activities, as well as in opportunities for personal development and interaction between staff and consumers. As a result, consumers can feel isolated and ignored, without the necessary supports to work toward and achieve recovery.	Service - Quality: Page 16
3.	It was identified by participants from all regions that there is no specifically identified, or independent advocate for mental health and mental illness issues on P.E.I. As a result, consumers, families and service providers do not know where to go for help, or may find themselves in a position of conflict.	Service - Quality: Page 16
4.	It was identified by all sectors and regions that there is a lack of access to psychiatrists and mental health professionals across the province. As a result, consumers are experiencing an absence of support and delays in diagnosis and treatment, and general practitioners are stalled by an inability to refer patients, receive feedback in a timely manner, and to become an integral part of the treatment through follow-up.	Service - Access: Page 16
5.	It was identified by participants from all sectors that there is a lack of funding to provide appropriate and effective programs. As a result, there is a lack of support for consumers, and service providers are over-burdened.	Service - Access: Page 17
6.	It was identified by consumers, family members and service providers that there is a lack of community-based psychosocial rehabilitation programs in the Kings County region. As a result, individuals in this region are isolated and limited in their ability to access community supports, employment opportunities, housing, life skills and social activities.	Service - Access: Page 17
7.	It was identified by the rural regions that Mental Health Emergency Response Teams in hospital Emergency settings and Community Assertive Outreach do not exist in all Health Regions. As a result, there is lack of supports and continuity for consumers and family members in these regions and as well, a greater burden placed upon general practitioners and psychiatrists.	Service - Access: Page 17
8.	It was identified by participants from all regions that as a standard practice, consumers and families (with permission of consumer) participate in the planning, delivery and evaluation of the treatment plan. Further, that the role of family as primary care-provider be recognized and supported, including being provided with information on diagnosis, available services, crisis management, effects of medications and expected outcomes. As a result, a more effective, responsive, treatment plan and support would exist.	Service - Consumer & Family Participation: Page 18



#	SUMMARY – IDENTIFIED SUPPORT NEEDS	Report Reference
9.	It was identified by participants from all regions that there is a need for consumers and family members to be involved in the service design, implementation, monitoring and evaluation at both the provincial and regional levels. It was further noted that accommodations should be made to facilitate consumer and family participation. As a result, a more effective system that would accurately reflect and address the needs of the consumer would exist.	Service - Consumer & Family Participation: Page 18
10.	It was identified by participants from all regions that self-help is an integral and proven model and should be fostered and supported. As a result, consumers and families would become more involved in supporting each other and benefiting from the experiences and coping skills of each other.	Service - Consumer & Family Participation: Page 19
11.	It was identified by participants from all sectors and regions that stigma is a major issue that impacts on almost every aspect of living with a mental illness. As a result of the stigma that currently exists, people are prevented from seeking help. It diminishes the quality of life for consumers and their families and prevents them from becoming an integrated and accepted part of their community. It was further identified that an effective national and provincial awareness strategy, positioning mental illness as a disease comparable to diabetes, cancer and heart disease, would be an effective method of reaching the masses who may not have a vested interest in mental illness.	Education: Page 20
12.	It was identified by participants from all sectors that there is a lack of education about people with mental illness in schools. It was further identified that programs should be available from primary schools through to post secondary facilities and that consumers are an important resource in the delivery of these programs. As a result, this education would help to demystify mental illness and would bring an informed attitude to the children through their lives and into their communities.	Education: Page 21
13.	It was identified by participants from all regions that general practitioners require more opportunities for education and information about mental illness and psychiatric medications. As result, there would be increased knowledge of a) the impact of mental illness on the consumer and b) the co-relationship between medications for mental and physical illnesses. Pharmacists were frequently identified as an excellent potential resource for doctors.	Education: Page 21
14.	It was identified by participants from all sectors that there is a lack of empathy and understanding of mental illness by some service providers, particularly Income Support staff and Emergency Unit nurses. It was further identified that these service providers would benefit from sensitivity training and basic education regarding mental illness, its symptoms and its effects. As a result, consumers would be provided more effective and appropriate supports and as well, reduce the increased stress and sense of worthlessness that may follow these contacts.	Education: Page 21
15.	It was identified by participants from all sectors and regions that there is a lack of education for family members regarding mental illness and how to provide care and support for the consumer. As a result, families are who are striving to support the consumer do so without education and coping strategies, leading to undue stress and mismanagement of the illness.	Education: Page 22



#	SUMMARY – IDENTIFIED SUPPORT NEEDS	Report Reference
16.	It was identified by participants from all sectors that consumers require more information about their illness including diagnosis, symptoms, medications, side effects, available services and contact information. As a result, this information can impact positively on recovery, decrease crisis and hospitalization, and can reduce the sense of hopelessness, of being ignored and overwhelmed.	Education: Page 22
17.	It was identified by participants from all regions that there is a lack of awareness regarding existing mental health services on Prince Edward Island. As a result, this can lead to an under-utilization of much needed services, inappropriate referrals and frustration on behalf of all sectors.	Education: Page 23
18.	It was identified by participants from all sectors and regions that the Income Support Program does not provide sufficient support to consumers to allow for quality of life issues. It was further stated that the same policies and guidelines that are applied to the general population are also applied to people with mental illness. As a result, this was seen as an unfair practice, as the needs of people with mental illness are unique and specific, and the failure to address them can have a direct impact on their quality of life and recovery.	Income Support: Page 24
19.	It was identified by all sectors and regions that the Income Support Program must be administered and delivered by trained staff who have an understanding and empathy for this target group, who recognize that consumers cannot always advocate on their own behalf, and who apply the policies fairly and consistently. As a result, individuals with mental illness will not be denied the support to which they are entitled and will feel respected and supported.	Income Support: Page 25
20.	It was identified that Income Support Programs must recognize the financial burden on the family and their role in providing on-going supports for the family member. As a result of this lack of financial support for consumers living with families, they are at increased risk of losing the support of their family which could result in more frequent hospitalization and a higher level of paid supports.	Income Support: Page 25
21.	It was identified that for consumers who are employed (or who have other sources of income such as Canada Pension Plan), and who have low income and high psychiatric medication costs and who do not qualify for Income Support, the cost of medications is prohibitive. As a result, affordability of medications is of major concern and hardship and consumers must often choose between food and medication, or will skip or decrease medication on their own in order to save on the costs.	Medications: Page 25
22.	It was identified that a process is required to address coverage for excluded medication not currently included on the Provincial Pharmacy list. As a result of the lack of full coverage, individuals may have to rely on medications with decreased efficacy.	Medications: Page 26
23.	It was identified that the current transportation policy should be expanded to address the transportation needs for individuals with serious and persistent mental illness. As a result of the current practice, there is discrepancy in interpretation and individuals have limited funds available to access necessary transportation needs.	Transportation: Page 26



#	SUMMARY – IDENTIFIED SUPPORT NEEDS	Report Reference
24.	It was identified by consumers, family members and service providers from all regions that work incentives must recognize the cyclical nature and the barriers to employment for individuals with serious and persistent mental illness. It was also noted that the value of work is considerable in supporting recovery. As a result of the current policies, consumers experience the anxiety of losing their benefits or the subsequent stress when benefits need to be recalculated.	Employment: Page 26
25.	It was identified that housing must be safe, affordable and appropriate. It was further noted that rent ceilings for individuals with serious and persistent mental illness must be applied beyond the allowable rate for single, non-disabled individuals. As a result, housing will better reflect the specific needs of the consumer.	Housing: Page 27
26.	It was identified that there is a need to advocate for and support the development of various levels of housing, from supported to independent. As a result, there will be an increased availability of appropriate housing to meet consumer needs.	Housing: Page 27
27.	It was identified that Home Care should be available for the long-term, on-going, needs of individuals with serious mental illness in the community. As a result, issues which often fall outside traditional models of home care including respite for care-givers, support for housekeeping responsibilities, and provision of necessary care for dependent children during periods of crisis or illness, would be in place.	Home Care: Page 28
28.	It was identified that support should be available to consumers seeking financial assistance to further educational opportunities. As a result, consumers, particularly those whose illness prevented completion of their education, would have increased opportunity for employment and quality of life.	Education: Page 28
29.	It was identified that the current policies should be expanded to provide extended dental care and dental maintenance. As a result, consumers would have enhanced dental care.	Dental Care: Page 28

