# Pain, Perseverance & Passion

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• A Report on the Support Needs of Individuals
with Severe and Persistent Mental Illness
on Prince Edward Island •

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*Prepared by the Canadian Mental Health Association/P.E.I. Division*

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# Support Needs for Individuals with Serious and Persistent Mental Illness

## EXECUTIVE SUMMARY

**"I want to be what I used to be."**
*- Mental Health Consumer*

**INTRODUCTION**
This summary provides an overview of the research project: Support Needs for Individuals with Serious and Persistent Mental Illness. A detailed report, "*Pain, Perseverance & Passion,*" has been prepared and submitted to the Department of Health and Social Services, Disability Support Program.

**BACKGROUND**
The Support Needs for Individuals With Serious and Persistent Mental Illness Project grew out of the Department of Health and Social Service's Disability Support Program (DSP), a division of Social Policy Development. As it currently exists, the Disability Support Program's focus is on those with physical and intellectual disabilities. A belief that individuals who experience serious and persistent mental illness have unique support needs, that currently are not being addressed, prompted the Department of Health and Social Services to contract with the Canadian Mental Health Association/PEI Division (CMHA), a non-profit mental health agency, to carry out the needs assessment project.

**OBJECTIVE**
To identify the principal support needs for individuals with serious and persistent mental illness and recommend strategies to address these needs.

**METHODOLOGY**
The support needs for people with serious and persistent mental illness (SPMI) were identified through focus groups, surveys and a call for written submissions. Consumer focus groups and family member focus groups were held in five regions across the Island. As well, surveys were sent to 400 service providers (governmental and non-governmental), general practitioners and psychiatrists. Ads were placed in four regional newspapers requesting written submissions from consumers and family members regarding their experience with mental health services on P.E.I. Anonymity was guaranteed for all people involved with each stage of the information gathering process.

The data collected was separated into topic categories, with attention being given to the number of times an issue was raised, the extent to which it was supported by others, and the emphasis that was placed upon it. From this process came the identification of the support needs.

Each stage of the process was reviewed with the CMHA Support Needs Advisory Committee, comprised of service providers, consumers and family members.

# Support Needs for Individuals with SPMI

## Principal Support Needs Summary & Prioritization By Region

• BASED ON FOCUS GROUP INPUT & SURVEY DATA •

| INPUT SOURCE - RANKING | | SUPPORT NEEDS WEST PRINCE | SUPPORT NEEDS EAST PRINCE | SUPPORT NEEDS QUEENS | SUPPORT NEEDS KINGS |
|---|---|---|---|---|---|
| FOCUS GROUPS | 1. | Services-Quality | Services-Quality | Income Support | Services-Quality |
| | 2. | Services-Access | Services-Access | Services-Quality | Education |
| | 3. | Education | Education* | Medications | Services-Access |
| | | | Medications* | | |
| | 4. | Medications | | Education | Medications |
| | 5. | Employment | Income Support | Transportation | Housing |
| | 6. | Income Support | Housing | Housing | Employment |
| | 7. | Housing | Employment | Services-Access | Transportation |
| | 8. | Transportation | Transportation | | Income Support |
| SERVICE PROVIDERS | 1. | Services-Access | Income Support | Services-Access | Services-Access |
| | 2. | Education | Housing | Income Support | Education |
| | 3. | Services-Quality* | Services-Access | Services-Quality | Transportation |
| | | Transportation* | | | |
| | 4. | | Transportation | Housing | Income Support |
| | 5. | Income Support | Services-Quality | Education | Services-Quality |
| | 6. | Housing | Education | Transportation | Departmental Funding |
| | 7. | Family/Consumer | Employment | Departmental Funding | Housing |
| | 8. | | Family/Consumer | Medications | |
| | 9. | | Medications | Family/Consumer | |
| | 10. | | Departmental Funding | Employment | |
| GENERAL PRACTITIONERS | 1. | Services-Access | Services-Access | Services-Access | Services-Access |
| | 2. | Services-Quality | Education | Services-Quality | Transportation |
| | 3. | | Services-Quality | | |
| | 4. | | Medications | Medications | |
| PSYCHIATRISTS | 1. | N/A | Services-Access | Services-Access | N/A |
| | 2. | | Employment | Employment | |
| | 3. | | Housing | Income Support | |
| | 4. | | Income Support | Medications | |

*** = Identical Ranking**

## RESULTS

The following list represents the primary elements of the key support needs for people with serious and persistent mental illness on Prince Edward Island, as identified by consumers, family members, service providers, general practitioners and psychiatrists. They have been grouped into three major categories: Services, Education and Income Support Policies.

### SERVICES

- Establish communication and cooperation amongst services and providers to promote consistency and continuity
- Improve access to psychiatrists and mental health professionals for family physicians
- Provide a supportive and therapeutic environment in psychiatric units
- Provide an independent advocacy forum for mental health issues
- Provide for the participation of consumers and caregivers (e.g., family members) in the planning, delivery and evaluation of mental health services
- Recognize and support the role of family as caregivers
- Ensure regional access to psychiatrists, day programs, emergency response personnel and community outreach.

### EDUCATION

- Advocate for a National public awareness strategy
- Develop an effective anti-stigma campaign
- Develop age-appropriate school awareness programs
- Increase and expand professional training and support for service providers
- Increase access to and expand caregiver and consumer education programs
- Establish information resources on mental illness for consumers and families
- Increase and expand dissemination of current information on programs and services

### INCOME SUPPORT POLICIES

- Address quality of life issues
- Ensure programs are administered and delivered by trained, empathetic, staff
- Medications: Establish processes to address excluded medications for Income Support recipients and coverage for low income, non-income support, recipients
- Transportation: Expand the current transportation policy to be responsive to support needs
- Employment: *Provide work incentives that address the cyclical nature of mental illness and the barriers to employment for consumers*
- Housing: Ensure that safe, affordable and appropriate housing is available to consumers

### OTHER CONSIDERATIONS

- Address Home Care issues (e.g., respite for caregivers, housekeeping support, care of dependent children)
- Support consumers in seeking financial assistance to further educational opportunities
- Address the need for increased dental care

Although not anticipated at the outset, the process used to gather information for this project turned out to be a valuable learning experience and demonstrated for us the uniqueness of the needs of people with a serious and persistent mental illness. The Canadian Mental Health Association/PEI Division appreciated the opportunity to undertake this study and looks forward to supporting the Department of Health and Social Services in the implementation of the recommendations.

# Pain, Perseverance & Passion

*"I want to be what I used to be."*
- Mental Health Consumer

"I want to be what I used to be …" speaks of the basic need that was heard at focus groups across Prince Edward Island. Consumers want to be contributing citizens, to be valued and respected. Consumers want to have a satisfactory quality of life, be able to participate and understand their illness. Consumers want to reclaim their lives … to be what they used to be. To achieve this, supports need to be available and effective. When one key support is absent or not responsive to the needs, a domino effect can take place resulting in illness, hospitalization, or major setbacks. The identified supports are addressed in the Support Needs section of this report, but the relationship between one mental health service to another is at the heart of this project.

## INTRODUCTION

The Canadian Mental Health Association/PEI Division is pleased to submit this report, particularly as it addresses the needs that Prince Edward Island consumers, families and service providers at all levels have identified. Support needs and access to mental health services are issues that impact Canadians nationwide. While mental illness impacts both young and old, from Newfoundland to the Northwest Territories, this report will be limited to the needs of Islanders, aged 18 to 60, who experience serious and persistent mental illness.

The completion of this report is timely. Across Canada, there have been a number of recent initiatives that are of similar context. The Michael J. Kirby, Health of Canadians Report, and Roy Romanow Report, Building on Values: the Future of Health Care in Canada, bring to light issues of national interest, naming mental health as the "orphan child" of health care. Other recent reports include Access to Mental Health Services: Issues, Barriers and Recommendations for Federal Action; Summary Information and Research Findings on Mental Illness in Canada; CMHA National's new Framework for Support III; the Position Paper on Federal Income Security Programs; Building Consensus for a National Action Plan on Mental Illness and Mental Health; A Report on Mental Illnesses in Canada and, just being released, is the Citizens for Mental Health: National Synthesis Forum Final Report. Other notable reports include: Dealing With Violence Towards People With Mental Health Problems and Home Care and People With Psychiatric Disabilities. While these and other reports bring national attention to the issues surrounding mental illness, there are still other provincial and territorial reports and studies which address related topics; e.g., Provincial Income Support Programs, barriers to employment and early interventions, that bring regional attention to these issues.

*"All we are asking for is what we're entitled to"*
- Family Member

## Who We Are

Canadian Mental Health Association/PEI Division was established on Prince Edward Island as a division of CMHA National in 1959. CMHA National, formed in 1918, is one of the oldest volunteer organizations in Canada.

CMHA/PEI is a non-profit mental health organization that promotes the mental health of all Islanders by providing information, strategies, supports and services, which enable people to manage and take positive charge of their lives to the best of their abilities.

With the support of the Department of Health and Social Services, Human Resource Development, United Way and Murchison Foundation, CMHA's Clubhouse Programs provide over 500 Islanders experiencing mental illness with opportunities to become involved in residential, prevocational, employment, education and social-recreation services. Through its three clubhouse programs, CMHA shares the goal of the Disability Support Program of helping people with disabilities reach a higher level of independence. Other programs and services offered by CMHA include: the Consumer and Family Support Program which provides the Journey of Hope education program for families, as well as resource materials and support for consumers and families across Prince Edward Island; the I'm Thumbody Program, a self-esteem program for Grade 3 students; the Signals of Suicide (SOS) Program, a suicide prevention program delivered to all Island Intermediate schools; the Applied Suicide Intervention Training (ASIST) for caregivers; and the White Cross Program for people with mental and emotional disorders.

## Background

The Support Needs for Individuals With Serious and Persistent Mental Illness Project grew out of the Department of Health and Social Service's Disability Support Program (DSP), a Division of Social Policy Development. As it currently exists, the Disability Support Program's focus is on those with physical and intellectual disabilities. A belief that individuals who experience serious and persistent mental illness have unique support needs that currently are not being addressed prompted the Department of Health and Social Services to contract with the Canadian Mental Health Association/PEI Division.

> *"I think it's wonderful that the Government is funding people to help us."*
>
> - Mental Health Consumer

The mandate of this project is to identify and make recommendations to address support needs for people, between the ages of 18 and 60, with serious and persistent mental illness across Prince Edward Island. For the purposes of this report, serious and persistent mental illness is defined as follows:

**Serious & Persistent Mental Illness**

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.

## Problem Perspective

In order to appreciate the scope of this project, it is necessary to provide some background about mental illness and the profound burden the illness causes in terms of suffering, disability, hospitalization and suicide. The World Health Organization has determined that mental illness is one of the largest contributors to disability worldwide. When the loss of life and ability is estimated using *Disability Adjusted Life Years* (DALYs)[a], more than 10% of the total burden of human disease and loss is attributed to mental disorders. Of the ten leading causes of disability worldwide, five are mental disorders: Major Depression, Schizophrenia, Bipolar Disorder, Alcohol Use Disorder and Obsessive Compulsive Disorder. By 2020, it is estimated that depressive illness will become the second leading cause of disease burden worldwide and the leading cause in developed countries such as Canada.

> *"You have to work twice as hard at living when you are bi-polar."*
> - Mental Health Consumer

## Scope Of Problem

It is estimated that 1 in 5 Canadians (or 20% of the population) will experience a mental health disorder in his/her lifetime. Best estimates available indicate that the national rate for severe and persistent mental illness in the Canadian population is approximately 3%. Using the 2001 Census figures for Canada and Prince Edward Island, we calculated the approximate incidence of serious and persistent mental illness for those populations (see Table #2 below). In addition, it should be noted there are many who will go undiagnosed and those who require help, but who may not receive it due to factors such as stigma and lack of access. According to Statistics Canada's National Population Health Survey, 68% of those with a mental illness, or symptoms and feelings associated with mental illness, will not seek professional help.

[a] Disability Adjusted Life Years (DALYs) are measures of the overall burden of disease and are calculated by combining: (1) losses from premature death, defined as the difference between actual age at death and the expectancy at that age in a low-mortality population, and (2) loss of healthy life resulting from disability.

*"Sometimes the nature of mental illness is that you're paranoid and that you can't seek help."*

- Mental Health Consumer

**TABLE #1: INCIDENCE OF SERIOUS & PERSISTENT MENTAL ILLNESS**

| LOCATION | POPULATION* | ESTIMATED SPMI** RATE | # OF PEOPLE WITH SPMI |
|---|---|---|---|
| Canada | 31,021,300 | 3% | 931,000 |
| P.E.I. | 136,700 | 3% | 4,100 |

*** Based on the 2001 Statistics Canada Census**
**** SPMI: Serious & Persistent Mental Illness**

This report serves as a further step towards addressing these issues. Within these pages are the support needs as identified by people with serious and persistent mental illness, service providers, physicians, psychiatrists and family members. This information comes from the source.

# METHODOLOGY

In order to reach the broadest number of people in diverse situations and of various experiences, information was gathered using a number of proven methodologies. It was important to ensure representation from all sectors and from all regions across Prince Edward Island. It is significant to note that the potential to identify and receive feedback from a broad sector of the Province is greatly enhanced by virtue of its small size. This was evident in the Canadian Mental Health Association's ability to meet with Provincial Mental Health Managers to solicit their support; to contact service providers directly; to receive strong support for focus group referrals; and the comfort level of participants. It is reasonable to expect that some of the experiences shared, personally and professionally, would span over a period of time, and that recent supports may not have been part of that experience. While this must be considered in the current context of the report, it is important not to assume that the issues have been addressed.

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*"My situation was eight years ago, before all these new changes were put in place, but it seems like nothing has changed."*

- Family Member

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**Focus Groups**

Focus groups were held in five regions across the Province. While typically the locations for the groups were identified to correspond with the Health Authority sites, one additional location was added in Souris.

A broad sector of service providers across PEI were contacted to provide referrals for the focus groups, including team leaders and directors from Psychiatric Units, Community Mental Health facilities, Clubhouse Programs and Consumer and Family Support Programs. A letter, outlining the particulars of the focus groups, was forwarded to the referral sources. The response rate was very positive, and focus group participants represented a wide range of needs and were referred from various sectors – this was imperative to ensure a balance in views. While participants of the consumer focus groups all had a serious and persistent mental illness, it was important that they be sufficiently stabilized to enable them to participate in the process.

There were two focus groups held in each of the five locations – a consumer focus group and one for family members. In total, 81 participants were involved. The groups were held in facilities that were deemed to represent a comfortable, non-threatening, space for those involved. Refreshments were provided to group participants. A Permission Form (See Appendix A, p. 11) was completed and signed by all individuals prior to discussions. Each focus group had one facilitator, one scribe, and one individual to assist with the process and record quotations from the participants. Refer to Table #2 for a summary of the focus groups.

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*"I'm really glad this is being done. I hope it helps."*

- Mental Health Consumer

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**TABLE #2: FOCUS GROUP SUMMARY**

| LOCATION | GROUP TYPE | DATE | FEMALE | MALE | TOTAL PARTICIPANTS |
|---|---|---|---|---|---|
| Alberton-Maplewood Manor | Consumer | October 16 | 4 | 3 | **7** |
| Alberton-Maplewood Manor | Family | October 16 | 6 | 3 | **9** |
| S'Side-Linkletter Motel | Consumer | October 20 | 4 | 5 | **9** |
| S'Side-Linkletter Motel | Family | October 20 | 5 | 2 | **7** |
| Ch'town-Inn on the Hill | Consumer | October 23 | 7 | 3 | **10** |
| Ch'town-Inn on the Hill | Family | October 23 | 3 | 2 | **5** |
| Souris-Breakwater Wellness | Consumer | November 3 | 5 | 3 | **8** |
| Souris-Breakwater Wellness | Family | November 3 | 5 | 3 | **8** |
| Montague-Memorial Hospital | Consumer | November 6 | 3 | 5 | **8** |
| Montague-Memorial Hospital | Family | November 6 | 8 | 2 | **10** |
| **TOTALS:** | | | **50** | **31** | **81** |

Questions for the focus groups were formatted to follow a logical progression, to generate conversation, and to elicit information. These questions were:

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 you face in trying to become or remain well.
4. What would help you with the problems you face?

Following the focus groups, the information gathered was placed into categories, with attention given to issues that were widely agreed upon by the participants, and issues that were given strong emphasis.

> *"If I had cancer, people would talk about it. If I have a mental illness, people will talk about anything else."*
>
> - Family Member

**Written Submissions**

Advertisements (see Appendix A, p. 6) were placed in the Guardian, the Journal-Pioneer, the Eastern Graphic and the Penny Saver, calling for written submissions from consumers and family members regarding their experience with mental health services on P.E.I. In total, eight submissions were received, allowing interested individuals to provide feedback to the process. Their comments were integrated into the focus group result categories.

> *"Sometimes I can do anything, but then other times I can't lift a pencil."*
>
> - Mental Health Consumer

**Surveys**

Surveys were sent to service providers, general practitioners and psychiatrists across the Province. Recipients were identified using mental health directories and by recommendations from various entities. The surveys were designed with length, language, readability, question order and information required in mind (see Appendix A, pps. 1 and 4). The general practitioner and psychiatrist surveys were condensed from the service provider survey. In total, 398 surveys were distributed, with 124 returned completed, just over 30%, a greater number than anticipated. A percentage of the surveys were sent to organizations that may or may not provide supports to this population, and thus, the response rate was lowered accordingly; it was determined that a larger mail out was best to decrease the risk of missing potential providers. The comments were put into corresponding categories and added to the focus group and written submission results to determine the ranking of the identified support needs. Confidentiality for participants was emphasized and guaranteed at every stage of the process.

**TABLE #3: QUESTIONNAIRE DISTRIBUTION & RETURN SUMMARY**

| TYPE OF ORGANIZATION | QUESTIONNAIRES DISTRIBUTED | # OF RETURNS | RETURN PERCENTAGE |
|---|---|---|---|
| Government | 222 | 51 | 23.0 |
| NGOs (non-government organizations) | 53 | 30 | 56.6 |
| Community Care Facilities | 29 | 7 | 24.1 |
| Support Groups | 8 | 3 | 37.5 |
| GP's/Psychiatrists | 86 | 33 | 38.4 |
| **TOTAL SURVEYS:** | **398** | **124** | **31.2%** |

> *"This group of people has been neglected consistently when resources are allocated. I hope this survey will be just the beginning of needed change."*
>
> - Family Physician

# SUPPORTS AND SERVICES

The following tables represent various supports and services identified by participants of the focus groups and identified in the surveys. Their inclusion indicates that participants were aware of their existence and/or that they had used them. It does not, however, indicate the quality of that experience.

These lists have been compiled using the responses to the focus group question *"Where can you go for help with your mental illness?"* and from the survey question *"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."*

The supports and services have been sorted into three categories: governmental (those that federal or provincial governments provide or are responsible for), non-governmental community, and informal (those that individuals access or develop on their own or through family, friends, etc.). It was evident that individuals are resourceful and that in addition to the structured supports that immediately come to mind, non-traditional, non-formal, supports also can be a complementary means of coping.

**TABLE #4: GOVERNMENTAL SUPPORT SERVICES**

| **TYPE/NAME OF SERVICE (Alphabetical listing – by row)** | |
|---|---|
| Addiction Services/counsellors | Adult education |
| Breakwater Wellness Centre | Brochures/pamphlets |
| Canada Mortgage & Housing Corporation | Case conference with family |
| Changeways | Child & Family Services |
| Community Mental Health counsellors | Counselling support (hospital) |
| Crisis response team | Day programs |
| Disability Support Program (DSP) | Doctor with nurse back-up |
| East Prince Mental Health | Emergency/Outpatients |
| Family doctor | Group therapy |
| Hillsborough Hospital | Holland College |
| Home Care | Hospital |
| In-house programs | Injection clinic |
| Human Resources & Development Canada | Income Support/Social Services |
| Legal system | McGill Centre |
| Member of Legislative Assembly (MLA) | Mental health services in other provinces |
| Montague Clinic | Montague Community Mental Health |
| Nurse | Occupational therapy |
| Outreach teams | Police |
| Psychiatric nurses | Psychiatric unit |
| Psychiatrist | Psychologist |
| Queen Elizabeth Hospital | Richmond Centre |
| Royal Canadian Mounted Police (RCMP) | Seniors' Day Care Program |
| Shock therapy | Souris Hospital |
| Surgeon | |

*"My counsellor cares and she makes a big difference. If it wasn't for her, I wouldn't have been able to get through the last year."*

- Mental Health Consumer

## TABLE #5: NON-GOVERNMENTAL SUPPORT SERVICES

| TYPE/NAME OF SERVICE (Alphabetical listing – by row) | |
|---|---|
| Alcoholics Anonymous | Canadian Mental Health Association |
| Career Bridges | Carousel of Friends group |
| Catholic Family Services Bureau | Church |
| Church groups | Clergy |
| Community care facility | Employee Assistance Program |
| Employment programs | Family Focus |
| Family Violence Prevention | Fitzroy Centre Clubhouse |
| Four Neighbourhoods | Group therapy |
| The Guardian self-help column | Help Line |
| Homewood | Internet support group |
| Job Shadow Program | Journey of Hope |
| Kids R First | Kids West |
| Literacy program | Medication |
| National Association for Mental Illness (US) | Notre Dame Place Clubhouse |
| Paraplegic Association | Pharmaceutical companies (medications paid through) |
| Pharmaceutical rep | Pharmacist |
| Physiotherapy | Prince County Family Services |
| Private mental health counsellors | Rape Crisis |
| Resource materials | Respite care |
| Retreat weekend (Catholic Church, Belcourt Lodge, Rustico) | Salvation Army |
| Schizophrenia Society | Self help groups |
| Survivors of Suicide | Transition and Support Services |
| West Prince Clubhouse | |

*"I went to the Clubhouse and it changed my life – housing, employment, socialization. It took me away from the isolation."*

- Mental Health Consumer

## TABLE #6: INFORMAL SUPPORT SERVICES

| TYPE/NAME OF SERVICE (Alphabetical listing – by row) | |
|---|---|
| Acupuncture | Aroma Therapy |
| Artistic expression | Bedroom space |
| Bible | Boyfriend/girlfriend |
| Chores | Co-workers |
| Courses | Diet (proper) |
| Drives in car | E-mail |
| Education | Employer (understanding) |
| Exercise | Faith |
| Family | Fellowship |
| Friends | God |
| Gym | Hobbies |
| Humour | Internet |
| Library | Life skills |
| Marriage | Meditation (tape) |
| Music | Pamphlets |
| Parents | Parents' friends |
| Periodicals | Pet |
| Phone | Physical activity |
| Prayer | Private time |
| Reading | Relaxation |
| Relaxation tapes | Socializing |
| Spirituality | Stress management |
| Study | Tai chi |
| Television | Vitamins |
| Volunteering | Walking (trail/country) |
| Work | Writing |

> *"I have a little room in my house with a statue of the Sacred Heart. I call it my quiet place. I go there twenty minutes every night."*
>
> - Mental Health Consumer

# SUPPORT NEEDS – GENERAL

Determining the support needs for individuals with serious and persistent mental illness was an exercise that spoke of pain, perseverance and passion. The pain that those personally affected by mental illness experienced was evident from the first point of contact through the focus groups and from one-to-one discussions; the perseverance of consumers, families and the service providers, who strive day-to-day to find better solutions for those impacted by this often debilitating illness; and the passion for an opportunity to make a difference.

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*"We'll do anything to help our son. Anything."*

- Family Member

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Information was gathered using the research methods previously described. The data was compiled and separated into categories to determine the specific support needs of people with serious and persistent mental illness. The frequency, emphasis, and the agreement amongst participants about an issue determined its ranking. Table #7 below summarizes the ranking of the support needs categories.

**TABLE #7: PRINCIPAL SUPPORT NEEDS – PROVINCIAL RANKING**

• Data From All Focus Groups, Regions and Surveys •

| RANK | SUPPORT NEEDS AREA | PROVINCIAL SCORE* |
|---|---|---|
| **1** | Services – Access | 296 |
| **2** | Services – Quality | 181 |
| **3** | Education | 139 |
| **4** | Income Support | 123 |
| **5** | Medications | 94 |
| **6** | Housing | 76 |
| **7** | Transportation | 57 |
| **8** | Employment | 27 |
| **9** | Family/Consumer | 11 |
| **10** | Departmental Funding | 9 |

*** The Provincial Score indicates the number of times each issue was brought up in all focus group discussions and survey comments.**

The support needs that were identified for Islanders were similar in nature to those being identified across Canada. The Citizens for Mental Health Report has identified seven key issues relating to mental health including housing, criminal justice, employment/income support, immigration/cultural needs, stigma/health promotion, capacity/empowerment and services for people with mental illness. Access to Mental Health Services: Issues, Barriers and Recommendations for Federal Action identified as their key issues stigma, lack of integration, shortage of mental health professionals, uneven regional distribution and quality of services, cross cultural and linguistic diversity and poverty. While cultural needs, linguistic diversity and

criminal justice issues were not identified as key support needs on Prince Edward Island, the other key issues fall in line with the National issues.

The support needs, as well as the resulting impact on those involved, are articulated on the following pages in descending order and have been divided into three primary categories, namely: Services, Education and Income Support. Although it was stated in the Support Needs Proposal, this report does not provide specific recommendations for actions. Many of the identified support needs would involve internal changes and as such, these would be best identified through joint discussion with all partners impacted by the specific support need.

Despite being ranked, every support need listed received considerable representation and should be considered a significant issue. While the issues were consistent across the Province, some support needs were given more weight in particular regions than in others, and these have been noted.

> *"What made the difference for me, was that one person took an interest in me."*
>
> - Mental Health Consumer

# Support Needs

• Pain, Perseverance & Passion •

# SERVICES

**INTRODUCTION:** In the past, individuals with serious and persistent mental illness were thought of as people for whom there was no hope of recovery. The main role of the formal mental health system was one of maintenance and control. Now that the potential for recovery is recognized, people can reach a point in their lives where they are free of the need for most formal mental health services. While they may continue to experience some symptoms, they can live productive and satisfying lives. Achieving recovery suggests reaching a stage where mental illness no longer dominates one's life; it reflects only one part of a person's identity. Clinical services, both medical and psychotherapy, are critical components of this recovery process. Service providers, consumers and family alike have identified the following key improvement areas in mental health service delivery:

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*"The cycle of wellness and unwellness is amplified by the lack of support. Support needs to be ongoing in order to remain well."*

- Mental Health Consumer

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## SERVICE QUALITY

**BACKGROUND:** *Respondents identified a need for a more centralized, integrated, mental health system and identified communication, consistency, lack of programming during hospitalization, access to staff and access to records as other key problem areas. Program delivery must be coordinated and service providers need to work as a team and include the individual, to ensure continuity of care in an efficient and effective manner.*

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*Some of the services we receive for psychiatric care are disjointed. You go here, you go there."*

- Family Member

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**SUPPORT NEEDS:**

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.**

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*"Connections with community services and linkages through various interagency committees helps to create a vehicle for communication and continuity of services for people with serious and persistent mental illness."*

- Service Provider

*"When I go to an appointment with my brother, very often I am correcting what is written on the charts. What does that tell me about the preparation for the meeting we are about to have?"*

- Family Member

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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.**

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*"My husband was admitted this summer. He was there for 3 weeks. He was basically stood in a corner.*

- Family Member

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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.**

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*"Sometimes I get awfully frustrated (at trying to get answers)."*

- Family Member

*"It is very difficult to advocate for the client when you are a member of the 'system'; i.e., no authority, no voice."*

- Service Provider

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## SERVICE ACCESS

**BACKGROUND:** *Mental Health programs and services require sufficient funding to provide quality supports to consumers and for service providers. Uneven distribution of services was also identified as a major issue, particularly in the Eastern and Western regions of the province. When individuals are removed from their communities, they are often separated from the natural support systems and informal caring networks that provide the kinds of financial, emotional, and social supports for recovery not found in formal services. Access to services can be costly, inaccessible and untimely. For maximum effectiveness, a treatment system should provide individuals with access to services where needed.*

**SUPPORT NEEDS:**

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.**

*"Outpatient psychiatry needs to be accessible in order that people will have the benefit of ongoing biologic therapy. To have a waiting list of six months is ludicrous."*

- Psychiatrist

*"I think the system is falling apart. We have more psychiatrists than ever, but as family doctors, we have less access than ever before. We often know these patients best, and often they are the most comfortable receiving treatment from us. I never know who the patient will see at the Centre, when they will be seen, and I receive little or no information on their treatment."*

- Family Physician

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.**

*"Mental health is not the 'sexiest' of fields. I have good things to say about these people but I think they are over-worked and not supported enough. The structure does not support their efforts."*

- Family Member

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.**

*"Consumers in rural communities have greater challenges – lack of resources, public transportation, financial resources, sense of isolation, social contact . . . we need day programs."*

- Service Provider

*"We need a place like Clubhouse, just so he doesn't feel alone, so he can see other faces – opportunities where he can meet others. All of his work experiences have been negative."*

- Family Member

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.**

*"I would like to go to my own hospital here, but they're shifting doctors so much that I'm not comfortable going."*

- Mental Health Consumer

## SERVICE – CONSUMER AND FAMILY PARTICIPATION

**BACKGROUND:** *Attention needs to be focused on the involvement of the informal networks, particularly the consumers and their families, and a validation of their role. Authentic participation by consumers and their families, in matters that directly affect their lives, should be a priority. This involvement would recognize the value of knowledge generated by life experience, seeing consumers and families as a new partner in planning and operating the mental health service system. Service providers, consumers and families across the Province identified that when all are involved, the outcome was improved.*

**SUPPORT NEEDS:**

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.**

*"My biggest problem is that I can't get information from the hospital. But if they were doing open-heart surgery, they'd tell you everything."*

- Family Member

*"My husband and daughter were a great support to me. Without them, I wouldn't be here."*

- Mental Health Consumer

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.**

*"Sometimes we have good ideas, time to be involved, a profound understanding of what our family member is experiencing and what might work for her over the long haul, but our voices are ignored."*

- Family Member

**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.**

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*"Since the support group's been here, I have had my first good summer in twenty-one years."*

- Mental Health Consumer

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# EDUCATION

**INTRODUCTION:** Stigma and the need for education and information regarding mental illness were identified as major issues across the Province. From region to region, sector to sector, respondents identified education about mental illness as a key factor in reducing the stigma of mental illness and in improving mental health supports in the service and employment sectors.

The serious stigma attached to mental illnesses is one of the most tragic realities facing people with mental illness in Canada. Arising from lack of knowledge and empathy, old belief systems and a tendency to fear and exclude people who are perceived as different, stigma has existed throughout history. It results in stereotyping, fear, embarrassment, anger and avoidance behaviors. It forces people to remain quiet about their illnesses, often causing them to delay seeking health care, avoid following through with recommended treatment, and avoid sharing their concerns with family, friends, co-workers, employers, health care providers and others in the community.

The lack of knowledge and understanding towards people with a mental illness has a detrimental effect on their ability to obtain services, the type of treatment and support they receive, their recovery, and their acceptance in the community.

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*"His friends basically abandoned him when he became mentally ill."*
- Family Member

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## ANTI-STIGMA

**BACKGROUND:** *Educating the public, service providers, employers and the media about mental illness is a first step toward reducing stigma and encouraging greater acceptance and understanding of mental illness. Consumers claim that the stigma associated with mental illness can be more disabling than the condition itself. Stigma reduction should be thought of as a long-term goal and be comprised of a number of strategies.*

**SUPPORT NEEDS:**

**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.**

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*"With a mental illness, people don't understand what is wrong with you. I'd give anything to have a physical illness."*
- Mental Health Consumer

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**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.**

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*"Not being able to work was a big loss. I didn't want people to think that I was just kicking around being lazy."*

- Mental Health Consumer

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## PROFESSIONAL TRAINING AND SUPPORT

**BACKGROUND:** *Consumers and families identified that for many individuals, the family physician is their first or primary contact with the health care system. Educating family physicians to properly recognize, diagnose, be knowledgeable of side effects of psychiatric medications, or know when to refer the affected individual to others, has a crucial role in maximizing the care that they provide. Other health professionals and service providers, particularly Income Support Staff and Emergency Unit nurses also provide essential services to those with mental illness. Areas to be addressed include:*

- *Nature and specific issues of mental illness*
- *Medications and their side effects*
- *The combined effects of medications for psychiatric and physical illness*
- *Use of empathy in service delivery*

**SUPPORT NEEDS**:

**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.**

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*"If the knowledge of mental illness was increased for medical staff, the comfort level with consumers would be increased."*

- Family Member

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**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.**

> *"Other service providers are not understanding or caring, especially Social Services."*
>
> - Service Provider

## CONSUMER/FAMILY EDUCATION

**BACKGROUND:** *Consumers and families directly affected by mental illness identified that they need information about the signs and symptoms of these illnesses, sources of help, medications, therapy and early warning signs of relapse; this was a strong theme across all Health Regions. Service providers also identified that outcomes would be improved by educating consumers and families in order to enhance their abilities to respond appropriately.*

**SUPPORT NEEDS:**

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.**

> *"You are dealing with 'what in heck happened to me and my family'. There should be something to tell you what resources are out there."*
>
> - Family Member

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.**

> *"Patients and families should receive information about the illness and the effects, similar to the prescription information sheets that people get when they purchase medication."*
>
> - Mental Health Consumer

## AWARENESS OF SERVICES

**BACKGROUND:** *Province-wide, Service Providers, General Practitioners, Consumers and Families identified that they do not have information regarding existing services, contact information, changes in services and access. The provision of information can be an access tool and it can provide support to all sectors.*

**SUPPORT NEEDS:**

**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.**

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*"The help is there, you just have to root it out, but you can get discouraged after trying two or three times."*

- Mental Health Consumer

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# INCOME SUPPORT

**INTRODUCTION:** The needs of people with Serious and Persistent Mental Illness change constantly. A cycle with periods of ability and periods of disability is a recurring pattern throughout their lives. Therefore, there are times when people manage the tasks of everyday life successfully, as well as times when they are unable to do so without assistance. Due to the cyclical nature of their mental illness, individuals often find themselves reliant on the Income Support Program on a short-term or long-term basis. Project respondents in all regions across the Province collectively identified that the existing policies do not recognize the specific and changing needs of individuals with serious and persistent mental illnesses, resulting in a system that has limited flexibility and is not always responsive to the varying support needs of this group.

## POLICY INTERPRETATION AND DELIVERY

**BACKGROUND:** *When people with serious and persistent mental illness experience periods of crisis, it can be difficult for them to have confidence and to feel good about their lives. For those who must rely on the Income Support Program to meet their basic needs, it is critical that compassion and understanding be key to the delivery of the program and that it recognize the varied and changing needs of this client group. Consumers, like all of us, have physical needs for decent food, clothing and shelter, and emotional needs for a sense of belonging through relationships with other people. They have a need to grow and develop through education and work; they require opportunities to pursue their own personal interests for enjoyment and relaxation. Often, consumers are forced to make choices between healthy eating and medication, socialization and housing. The significant difference that this makes for people with mental illness is that it is much more difficult to achieve and maintain mental wellness when quality of life is inadequate. Respondents made particular note of their need to recognize the value of increased physical activity and proper nutrition, and the importance of supporting these needs for individuals with serious mental illness.*

**SUPPORT NEEDS:**

**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. If 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.**

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*"Not having to worry about finances is a big factor in my being well."*
- Mental Health Consumer

*"A small investment in some areas, for example medications, transportation and housing, can have huge payoffs in quality of life and self-support."*
- Service Provider

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**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.**

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*"We need more cooperation with Income Support so that individuals aren't always feeling like second class citizens."*

- Service Provider

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**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.**

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*"If I couldn't live with my Mom, I would have to leave the Island."*

- Mental Health Consumer

*"When my husband took sick, I had to leave my work. Now Social Services is saying we're not eligible for support."*

- Family Member

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## MEDICATIONS

**BACKGROUND:** *Psychiatric medications are an expensive, yet medically necessary component of treatment for people with a serious and persistent mental illness. Mental health consumers tend to be among Canada's poorest citizens and many depend on the Income Support Program for drug coverage. The cost of psychiatric medications was discussed and noted at every level and region across the Province. For individuals who are in receipt of Income Support, the concerns centered around the side effects, efficacy and coverage for exceptional medications; for those not eligible for Income Support, the concerns were primarily cost related.*

**SUPPORT NEEDS:**

**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.**

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*"He's cut back on his medications so the pills will go further. He's taking over half of his income for medications."*

- Family Member

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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.**

> *"We need to expand accessible medication coverage by provincial plans."*
>
> - Family Physician

## TRANSPORTATION

**BACKGROUND:** *Policies should reflect the need for transportation to include appointments, programs, employment, education, grocery shopping and other general transportation needs, as well as provide for some level of social and physical health component. While current policies do provide for varied transportation costs for recipients of income support, there are inconsistencies from region to region, staff to staff, and consumers and service providers reported that often those who do not have support, or cannot lobby on their own behalf, are not afforded the same benefits as others.*

**SUPPORT NEEDS:**

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.**

> *"When there are inadequate transportation funds, there is difficulty getting to possible employment, self-help groups, education programs, or medical appointments."*
>
> - Service Provider

## EMPLOYMENT

**BACKGROUND:** *Work …works! Work can provide a profound meaning in your life – a sense of who you are among other people. Working allows you to contribute to your support and community, develop relationships and provide a structure upon which you can direct and organize your days. Most individuals with serious mental illness are capable of working either on a full-time or part-time basis. Many have been diagnosed with mental illness as youth and have not developed a work history. Medications and their side-effects …sleep disturbances, nausea, lack of motivation, excessive weight gain, poor concentration, tremors, sensitivity to sun exposure, inadequate fine motor skills, etc. …create employment barriers that must be overcome, adapted, or accommodated.*

**SUPPORT NEEDS:**

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.**

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*"Supports are needed with built-in incentives to try employment without major losses and red tape to get back on financial assistance."*

- Service Provider

*"Jobs give them a reason to get up. That's like a success story of how it could be."*

- Family Member

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## HOUSING

**BACKGROUND:** *The need for decent, affordable and appropriate housing was a province-wide message, but a basic difference was recognized between the urban and rural regions. Many consumers in rural areas were identified as living with aging parents with few options within the region. Parents expressed concerns about the lack of options, their limited ability to provide housing on a long-term basis, and the limited funds available to provide for the care and support of their family members. Urban areas expressed the need for housing to provide a learning environment with built-in supports. For others, the limited, allowable, rent ceiling for single individuals was of concern.*

**SUPPORT NEEDS:**

**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.**

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*"Housing is a big issue. There is a need for less expensive housing, which will help clients gradually move towards independent living. Also, the waiting lists are too long."*

- Service Provider

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**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.**

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*"We need housing for consumers who require supervision, but are not appropriate for community care."*

- Service Provider

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## OTHER CONSIDERATIONS

**BACKGROUND:** *A number of other important issues were raised during the course of the project. While they are not included in the key results, they are important to note and work toward implementing strategies for solutions.*

**HOME CARE:**

**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.**

**EDUCATION:**

**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.**

**DENTAL CARE:**

**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.**

# BEST PRACTICES

**INTRODUCTION:** While the primary purpose of the Support Needs Project was to identify gaps in support needs, it is important not to lose sight of successful existing models. Throughout the various research phases, examples of existing supports were identified by consumers and families as being effective and were thus considered to be successful or "best practice" models. As in any measure of services, the view of those most impacted were seen as invaluable. Where the following services existed, they were seen as key interventions and should remain and be supported as part of a continuum. In some situations, the services existed, but the individuals were not aware of them in their region, reinforcing the need to create awareness. The supports identified are not intended to be all-inclusive, but represent the models that were most highly noted by service users. The are listed below in alphabetical order.

**Assertive Outreach Team ("McGill Model")**

The Community Option Program at McGill Centre was expanded in February, 2003, to include an Assertive Outreach component, now known as AOT. This team works under the direction of the Community Options Clinical Coordinator. The Assertive Outreach Team is a modified form of the Best Practice model of Assertive Community Treatment Team, (ACT), also known as Intensive Case Management, which is well known throughout Canada and the USA.

The Assertive Outreach Team is multi-disciplinary team with a Mental Health Social Worker, Occupational Therapist, Mental Health Support Workers and a Registered Nurse. The hours of service were expanded to 12 hours on Monday through Friday from 8:00 am to 8:00 pm and on Saturday and Sunday from 8:00 am to 4:00 pm. This is the first team in Community Mental Health on P.E.I. to provide seven days a week service (formal ACT teams run 24 hours per day, 7 days a week).

A specific client group was targeted and the ACT model admission criteria utilized. This includes: 1) Clients with serious and persistent mental illness of a psychotic nature that seriously impair their functioning in community living (those who have SPMI, complicated by a concurrent disorder, are appropriate). 2) Significant functional impairment; e.g., daily living tasks, repeated evictions or loss of housing. 3) Continuous high-service needs; e.g., repeated hospitalization, severe major symptoms, coexisting substance use disorder, high risk or recent history of criminal justice involvement, inability to participate in traditional office-based services.

A similar model has been implemented in the East Prince Region, but does not include the extended hours.

> *"There have been times in the past that our son's illness has been very acute and the police had to be involved. But now, with the (Assertive) Outreach, this seems to be all addressed."*
>
> - Family Member

**Assertive Outreach Team ("Rural Program")**

The Community Mental Health Outreach Program was introduced to the Kings Health Region in May, 2003. The Outreach Team in Eastern Kings consists of two Community Outreach workers and two Community Mental Health nurses who provide direction to the workers. Because the team is not multi-disciplinary, other existing resources in the region are utilized (Occupational Therapist, DSP worker, financial assistance experts, a dietician and a family physician) to complement the team's skills and broaden the services offered. The program's hours of operation are Monday through Friday, 8:00 am to 4:00 pm.

The targeted client group includes 1) people suffering from serious and persistent mental illness; 2) people with significant functional impairment and 3) people with high service needs such as those requiring repeated hospitalization or those with a coexisting substance use disorder. Currently, the programs offered include assertive outreach, step down and maintenance outreach.

Because the region lacks the infrastructure and resources that exist in larger centres; e.g., recreational facilities, availability of low cost housing, clubhouses to deliver day programs and funding for programs, our Outreach Program is tailored to meet the specific needs of our multi-challenged clients.

A similar program is available in the Southern Kings area.

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*"My Counsellor (Assertive Outreach) cares and she makes a big difference. It if wasn't for her, I wouldn't have been able to get through the last year."*

- Mental Health Consumer

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**Clubhouse Program**

Clubhouse is an international, psychosocial, rehabilitation program model for adults experiencing mental illness. There are more than 300 affiliated clubhouses operating in 24 countries around the world. Clubhouses are based on the realization that recovery from serious mental illness must involve the whole person in a vital and culturally sensitive community. Clubhouse is a "supportive community" that offers a broad approach to helping its members grow towards more independent and productive lives. Participants are members, not patients or clients. The clubhouse focuses on members' strengths, talents and abilities. It provides participants with an opportunity to set and achieve goals, access support and feel valued and needed. Through work-based activities, members work side-by-side with staff, performing all the necessary tasks in the day-to-day operations of the clubhouse. There is a feeling of cooperation and ownership within the clubhouse. All work is done to help members develop new skills and to improve self-confidence.

Clubhouses offer an array of services from which members can choose as their needs and life goals indicate. Members can take advantage of vocational rehabilitation, employment opportunities, housing support services, social and recreational programs, supported education and advocacy.

There are three clubhouse programs in Prince Edward Island: West Prince Clubhouse in Alberton; Notre Dame Place Clubhouse in Summerside, and Fitzroy Centre Clubhouse in Charlottetown. Both the Charlottetown and Summerside programs have received three year accreditation. Depending on location, programs are open 5-6 days per week as well as 1-2 evenings per week.

> *"I went to the Clubhouse and it changed my life – housing, employment, socialization. It took me away from the isolation."*
>
> - Mental Health Consumer

**Crisis Response Model**

The Crisis Response Model has been implemented at both the Prince County and Queen Elizabeth Hospitals. They provide a service that supports the Emergency Department staff, psychiatrists and physicians in managing mental health crisis. The overall goal of the service is to provide an enhanced emergency mental health/psychiatric response, assessment and referral service at the PCH and QEH Hospital Emergency Departments for those individuals who present in emotional and/or psychological crisis.

While the Crisis Response Teams are guided by the Provincial Mental Health Crisis Response Guidelines, the services are customized to reflect regional differences. The Prince County Hospital Crisis Response Team is staffed by two full time Social Work positions and provides coverage from 8:00 am to 6:00 pm weekdays and emergency coverage for weekends. The Queen Elizabeth Crisis Response Team is staffed by three full time Nursing positions and provides coverage from 8:00 am to 8:00 pm, seven days per week.

As well as providing direct supports to the individual in crisis, the Crisis Response Team has a responsibility towards family or the support network who accompany an individual in crisis. This includes seeking their input, supporting by listening to their concerns, protecting their safety and giving accurate and relevant information.

**Journey of Hope Program**

The Journey of Hope Program is an international program of the National Journey of Hope Institute. A program of the CMHA Consumer and Family Support Program, and funded by Department of Health and Social Services and the United Way, Journey of Hope is a provincial, family-to-family, education and support program delivered by trained family member volunteers. The education component is an eight-week program designed to educate and support family members of someone experiencing a mental illness. The course covers:

- The major medical aspects of schizophrenia, bipolar disorder, schizoaffective disorder, depression and obsessive-compulsive disorder
- Detailed information on medications
- Immediate coping skills for dealing with the different cycles of each illness, including crisis planning
- Coping skills useful in the more stable periods
- Information on community services

- Collaboration with professionals
- Recovery and rehabilitation
- Mental Illness and substance abuse

An on-going support group is made available to family members.

> *"My husband and I took the Journey of Hope in Montague, and again here, because we got so much out of it."*
>
> - Family Member

**Professional Supports**

Other professional supports including Psychiatrists, Family Physicians and Mental Health Counsellors were all identified as vital services to consumers and families. The experiences of individuals were varied but those who had positive relationships with these professionals spoke highly of the impact they had on their recovery and the value of those supports and relationships.

> *"Any quality of life my son has had over the past ten years are directly as a result of the dedicated people in the mental health system. I couldn't say enough about the people in this service. They do a lot with what they have."*
>
> - Family Member

**Self-Help**

CMHA supports the development and administration of support self-help groups. Self-help, or mutual support is a process wherein people who share common experiences, situations, or problems can offer each other a unique perspective that is not available from those who have not shared these experiences. Self-help groups are run by and for group members. Professional providers may participate in the self-help process at the request and sanction of the group and remain in a consultative role.

Several tools are available from CMHA to assist self-help groups including: Resource Rooms; Self-Help Column (Guardian and Journal Pioneer) and the '*Directory of Self-Help Groups and Community Resources on Prince Edward Island*'.

> *"Self help groups are one of the best sources of help. The best people to talk to are the people who have been there. It's a connection that family and professionals, no matter how good their training, can't make as easily."*
>
> - Mental Health Consumer

**Subsidized Housing Programs**

Home Base Inc., a subsidiary of the Canadian Mental Health Association, provides individuals with decent, affordable and safe housing in the Charlottetown and Summerside regions. The Clubhouse programs manage the housing services in their respective region. Clubhouse staff assist eligible members in accessing and maintaining decent affordable housing opportunities that best meet each individual's needs. The housing is established to be open-ended to provide tenants the security in housing they have often lacked. Housing opportunities provided by Home Base Inc. include:

*Longworth House*: This is a ten-bedroom house that provides a home-like environment. Tenants who live in the house are independent enough to function in a co-operative living situation with part-time supervision. The philosophy of the house is to meet the daily needs of tenants, yet allow for personal growth and development.

*Fitzroy Centre and Notre Dame Place Apartment Complexes*: Fitzroy Centre has seventeen apartments and Notre Dame Place has ten. All these units are furnished and provide independent living opportunities for tenants while at the same time providing supports as needed to enable them to live on their own. Emphasis is on maintaining independence. Due to the proximity of these apartments to the Clubhouses, the members who live in these units have the opportunity to access increased levels of staff support as required. The rent is geared to income for qualifying tenants.

*181 Kent Street Apartments*: This complex has eight independent furnished apartment units. Members who live in these apartments have often achieved a level of independence that requires only occasional support or intervention. These apartments are located a short distance from the Clubhouse. The rent is geared to income for qualifying tenants.

*Community Based Apartments, Charlottetown/Summerside*: The clubhouses currently operate fifteen of these units in Charlottetown and three units in Summerside. These are independent apartments that are located in various locations in both cities. The Clubhouse leases these apartments from the landlord and in turn sub-leases them to members at a rate that is geared to income. These apartments are rented to clubhouse members who are independent and whose income will allow them to benefit from the subsidy.

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*You lessen people's worries by having safe affordable housing so their home life brings them contentment and security.*

- Service Provider

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# CONCLUSION

While there were success stories, there was also pain and frustration identified by the participants involved in the focus groups and surveys. Frequently, consumers, families and caregivers did not know where to turn for help, especially in times of crisis. Many did not feel supported and understood. The issue of stigma was alive and well.

Time and again consumers and their families stated that they were appreciative of the opportunity to take part in the focus group, to come together with others who were dealing with similar issues, and to have a chance to speak about these issues. The survey response rate indicated that service providers, family physicians and psychiatrists also appreciated the opportunity to provide input into the support needs for individuals with serious and persistent mental illness and are committed to making a difference. The feedback from all sectors provided the basis for this report.

The process used to gather information for this project turned out to be a valuable learning experience and reinforced the uniqueness of the needs of people with a serious and persistent mental illness. While fiscal restraints must be recognized, the implementation of the identified support needs will have a long-term impact on the health and recovery of this population, in turn, reducing the current demand on the acute services. Not all support needs identified require monetary allocations and not all support needs were identified as the sole responsibility of Government. Implementation of the support needs requires a shared partnership between Government, community, consumers and family.

The Canadian Mental Health Association/PEI Division appreciated the opportunity to undertake this study and along with consumers, families, service providers, physicians and psychiatrists, look forward to supporting the Department of Health and Social Services in the implementation of the actions and strategies that address the support needs for individuals with serious and persistent mental illness.

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*"I want to be what I used to be."*

- Mental Health Consumer

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