CARING TOGETHER: FAMILIES AS PARTNERS IN THE MENTAL HEALTH AND ADDICTION SYSTEM

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FAMILY MENTAL HEALTH ALLIANCE

camh
Centre for Addiction and Mental Health
Centre de toxicomanie et de santé mentale

CANADIAN MENTAL HEALTH ASSOCIATION, ONTARIO
L'ASSOCIATION CANADIENNE POUR LA SANTÉ MENTALE, ONTARIO

Ontario Federation of Community Mental Health and Addiction Programs

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This project was initiated by the Family Mental Health Alliance (FMHA). FMHA is an alliance of family organizations and individual family members working to develop a stronger voice for families in the mental health and addiction system, to strengthen the supports provided to families and to raise awareness of issues from a family perspective.

Members of FMHA include:

- Individual Family Members
- Across Boundaries, An Ethnoracial Mental Health Centre
- Family Association for Mental Health Everywhere (FAME)
- The Family Council: Empowerment for Families in Addictions and Mental Health
- Family Outreach and Response Program (FOR)
- Family Resource Centre at the Centre for Addiction and Mental Health (CAMH)
- Family Support Program, Toronto East General Hospital
- Family Support Program, Toronto Western Hospital, University Health Network
- Hong Fook Mental Health Association
- Mood Disorders Association of Ontario (MDAO)
- Schizophrenia Society of Ontario (SSO)

This project is a partnership initiative between:

Family Mental Health Alliance (FMHA)
Canadian Mental Health Association, Ontario (CMHA)
Centre for Addiction and Mental Health (CAMH)
Ontario Federation of Community Mental Health and Addiction Programs (OFCMHAP)

ACKNOWLEDGMENTS

The people whose experiences are featured in this report live, every day, with the consequences of a loved one's mental health or addiction problem. They have struggled, in some cases for many years, to find support, information and validation in a health care system that rarely acknowledges the important role they play and, even more rarely, meets their needs. They are vocal advocates for their relatives and, despite the challenges with which they live, they remain hopeful, passionate and committed to ensuring that their experience benefits others.

We are grateful for their generosity in sharing their stories. Appendix A provides a full narrative of the experiences of seven people whose family members have been diagnosed with serious mental health or addiction problems. We are indebted to those individuals for what they have taught us, and for their enormous contribution to the health care system.

We are also grateful to Valerie Johnson, Johnson Consulting and Ursula Lipski, Schizophrenia Society of Ontario for research and writing of this report.

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A NOTE ABOUT LANGUAGE

Many terms have been used to describe people with mental health and addiction problems, the people who care about them and the relationships between them. This document intends that these terms be used as follows:

Addictions refer to problems related to substance use or gambling.

Concurrent disorders refer to the co-occurrence of both mental health and addiction problems.

Consumer refers to a person who has experienced a serious mental heath or addiction problem. This term should be read as including those who choose to describe themselves as "clients," "patients," "survivors" and "consumer survivors."

Family describes people with a strong and emotional, psychological and/or economic commitment to one another – regardless of the nature of their relationship. "Family" can include those connected by biology, adoption, marriage or friendship. Ultimately, it is the person seeking services (whether it be a family member or a consumer) who defines his or her own "family."

Mental health problems refer to a wide range of mental health issues that include problems related to mood, anxiety, impulsivity and cognitive/perceptual processes.

Relatives refers to people with a formally defined connection (whether biological or not) to one another.

Caregiver is defined as someone who provides unpaid care in their own home or in the recipient's home to a family member, friend or neighbour who has been diagnosed with a mental health or addiction problem.[1]

Provider (or **Service Provider**) refers to a professional (e.g. social worker, case manager, psychiatrist, nurse, etc.) who is paid to provide mental health and addiction services.

INTRODUCTION

This paper highlights the important role of families within the mental health and addiction system and the impact of mental health and addiction problems on families. It documents the experiences of families, describes the critical role they play and calls for increased resources for the services and self-help organizations that support them.

The well-being of families is interconnected with the well-being of consumers. When consumers are better served by the mental health and addiction system and when consumers' needs are acknowledged and met, families benefit tremendously. Although we focus on family issues in this paper, we support consumers in their advocacy efforts for changes to the mental health system and their calls for increased funding and supports to consumers. Supporting consumers is central to supporting families.

EXECUTIVE SUMMARY

The incidence, impact and consequences of mental health and addiction problems are well known. What is less well known and appreciated is the tremendous but often invisible role that family members have within the mental health and addiction system, and the impact of mental health and addiction problems on families.

This paper outlines the important role of family, the impact of mental health and addiction problems on families, the needs of families, and the benefits of involving them in care provision and decision-making. It serves as a blueprint for governments, decision-makers and mental health professionals on how to involve families in the system and support families to meet their needs.

The presence of a serious mental health or addiction problem can have significant consequences for all family members. The chronic stress that family members' experience, along with the practical demands of caring for their relative, can have an impact on their day-to-day living, health, social and family relations, careers and financial situation.

Family members who care for relatives with mental health or addiction problems serve in a variety of roles. They may:

- Act as informal case managers, encouraging and supporting treatment; identifying and securing housing; and arranging for income assistance
- Provide crisis intervention
- Assist with system navigation
- Advocate on behalf of their ill relative
- Monitor symptoms and support adherence to treatment plans to lessen risk of relapse
- Provide housing, and assist with activities of daily living, including paying bills
- Maintain records of previous treatments, medications and hospitalizations
- Provide information on the context of a loved one's life, to assist professionals in understanding them as a whole person

Numerous studies have shown that family involvement in these roles results in significant benefits – for both the individual and the health care system. Benefits include:

- Decreased rates of hospitalization and relapse
- Enhanced adherence to treatment choices
- Increased rates of recovery
- Decreased involvement with the criminal justice system
- Savings to the mental health and addiction systems

Families are a critical piece of the complex network of people, organizations and institutions that make up the mental health and addiction system and they cannot be overlooked. The needs and contributions of families living with mental health and addiction problems must be addressed. The frequently overwhelming stress families experience requires that they have access to services and supports designed to answer their questions and respond to their concerns. The

critical role they play demands that they be recognized as partners in the care of their loved ones. The valuable contribution they make to Ontario's health care system justifies significantly greater investment in family programs and services.

With that in mind, we call on the Ontario Ministry of Health and Long-Term Care, the Local Health Integration Networks and addiction and mental health service providers to recognize and support families in the following four areas:

I. ENHANCING SERVICES AND SUPPORTS FOR FAMILIES

- Creation of a protected per capita funding envelope for family programs, including respite
- Improved access to consumer support services (i.e. social / recreational, education, training, employment programs)
- Provision of family education, support and counseling by clinical addiction and mental health programs
- Comprehensive, well coordinated, easy-to-access, culturally competent programs available in each LHIN
- In-service training to educate and sensitize staff to working with families

II. SUPPORTING FAMILY PEER SUPPORT AND FAMILY ORGANIZATIONS

- Annualized and sustained funding for peer support and mutual aid organizations
- Equitable access to peer support in every LHIN
- Integration of peer support within existing addiction and mental health programs
- Training to ensure staff are knowledgeable of and supportive of peer support and mutual aid, and they make appropriate referrals

III. INVOLVING FAMILIES AS PARTNERS IN CARE, REHABILITATION AND RECOVERY

- Development of a MOHLTC policy framework and standards for working with and integrating families as members of the care team
- Family led education to assist practitioners in working with, and understanding families
- Organizational policies and procedures to support working with families
- Core curriculum on working with families incorporated into accreditation training for professionals

IV. INVOLVING FAMILIES AS SYSTEM PARTNERS

- Formal recognition of families as key stakeholders by MOHLTC
- Inclusion of family representatives on LHIN advisory committees
- Inclusion of family representatives on boards and committees of mental health and addiction organizations

BACKGROUND

The statistics are staggering. At some point in their lives, most people will be touched by a mental health or addiction problem –one that they experience either directly or through a family member, friend or colleague. Many will struggle with both an addiction and a mental health problem at the same time.

WHO IS AFFECTED

- Canadians have a one in five chance of having a mental illness in their lifetime[2]
- Major depression impacts 8% of adults; 1% will experience bipolar disorders; 12% will suffer mild to severe impairment due to anxiety disorder; and 1% will be affected by schizophrenia[3]
- 18% of adolescents (aged 15 – 24) report a mental illness or substance abuse problem
- 90% of people who commit suicide have a diagnosable mental illness[4]; there are approximately 4000 suicides in Canada each year
- 13.6% of Canadians are high risk drinkers.
- Current Canadian drinkers (of all ages and drinking levels) report some form of harm in the past year due either to their own alcohol intake (20%) or to someone else's (33%).
- 10% of days spent in hospital are as a consequence of substance abuse.[5]
- Drinking alcohol during pregnancy is the leading cause of birth defects in North America.
- 5% of gambling Canadians are problem gamblers.[6]
- 30% of people diagnosed with a mental illness also have a substance abuse problem.

SOCIAL AND ECONOMIC IMPACT

- Mental illnesses contribute more to the global burden of disease than all cancers combined.[7]
- Disability represents 4% to 12% of payroll costs in Canada; mental health claims (especially depression) have overtaken cardiovascular disease as the fastest growing category of disability costs in Canada.[8]
- One in seven hospitalizations, and one-third of all days in hospital involve patients with a mental illness.[9]
- The unemployment rate among people with serious mental illness is 70 – 90%.[10]
- The annual economic costs of mental illness to Canadian society are estimated to be $14.4 billion[11]
- The annual economic costs of alcohol abuse are estimated to be $14.6 billion and $8.2 billion for illegal drug use[12]
- Schizophrenia alone costs the Canadian economy $6.85 billion annually[13]

The incidence, impact and consequences of mental health and addiction problems are well known. What is less well known and appreciated is the tremendous but often invisible role that family members have within the mental health and addiction system, and the impact that mental health and addiction problems and the system itself have on families. As noted in Out of the Shadows at Last, (commonly known as the Kirby/Keon Report), the final report of the Standing Senate Committee on Social Affairs, Science and Technology, "caregivers feel excluded, ignored by the mental health, mental illness and addiction system in Canada. Ironically, it is these same family members who often provide most of the care and support to people living with mental illness."[14]

As Ontario moves forward with transforming the health care system and establishing Local Health Integration Networks (LHINs), the province is well positioned to make improvements to the mental health and addiction system. In this context, families represent a critical piece of the complex network of people, organizations and institutions that make up the system and cannot be overlooked.

This paper outlines the important role of family, the impact of mental health and addiction problems on families, the needs of families, and the benefits of involving them in care provision and decision-making. This report serves as a blueprint for governments, decision-makers and mental health and addiction professionals on how to involve families in the system and support families to meet their needs.

IMPACT ON FAMILIES

The presence of a serious mental health or addiction problem can have significant consequences for all family members. Families experience the impact and burden of mental health and addiction problems in their roles of caregivers as well as simply by virtue of being a family member. Parents, partners, siblings and children react, and cope, in different ways, at different stages of a mental health or addiction problem.[15] The chronic stress that family members' experience, along with the practical demands of caring for their relative, can have an impact on their day-to-day living, health,[16] social and family relations, careers[17] and financial situation.[18]

IMPACT ON DAY-TO-DAY LIVING

For someone with a mental health or addiction problem, and for their family, life can be chaotic and unpredictable. Symptoms may appear one day and abate the next. Behaviour that a week ago was unthinkable becomes the "new normal" the following week. Families may feel powerless to do anything other than worry[19] and virtually all aspects of a person's life – from vacations to shopping to simple downtime – may change:

- In a study of 362 caregivers of someone with schizophrenia, 65% indicated that they rarely or never have enough time off from caregiving to pursue their own activities.[20]

> *"I had to take my daughter to buy her wedding dress. Her mother wasn't sober that day."*

- Life events that are normally a cause for celebration become a source of stress and conflict.
- 42% of families of people with schizophrenia indicate that their caregiving responsibilities frequently or always interfere with their ability to take a vacation.[21]
- Family members tend to spend a significant amount of time in caregiving roles; families of people with schizophrenia in the UK spend an average of 20 hours per week, the equivalent of a part-time job, in a caregiving capacity.[22]

IMPACT ON HEALTH AND WELL-BEING

Feelings of confusion, anxiety, stress, guilt, shame, self-blame, depression, fear, and anger are common among caregivers.[23] These feelings generally change over time and according to the stage of the illness and cycle up and down coinciding with their family member's condition. Over time, however, families tend to experience changes in their health and well being:

> *"You're absolutely besieged on every front. Taking care of yourself is the last thing you do."*

- Caregivers have higher rates of emotional and anxiety disorders, and are twice as likely as non-caregivers to use mental health services for their own problems.[24]
- Almost one quarter (23%) of caregivers of people with schizophrenia report they are taking medications prescribed by a doctor or psychiatrist to help with their emotional health.[25]

> *"It isn't just that you're dealing with someone who's ill. The nature of this illness means that you're constantly traumatized. We suffer from all the symptoms of Post-Traumatic Stress Disorder."*

- 70% of caregivers of people with schizophrenia feel their health has suffered because of their caring role.26
- Spouses of problem drinkers report high rates of anxiety, depression and low self-esteem.[27]
- Siblings of people whose schizophrenia creates behavioural disturbances display high levels of distress.[28]

IMPACT ON SOCIAL AND FAMILY RELATIONS

> *"I lost a 30-year friendship. I leaned on them so much, they were overwhelmed."*

When most people are diagnosed with a significant physical health problem, they seek support from family and friends. Friends and family often rally round to express concern and offer assistance, whether or not support is requested. When a family member has a serious mental health or addiction problem, the response can be quite different. Stigma and discrimination,[29],[30] and a lack of understanding can mean that families and consumers sometimes conceal mental illness or addiction problems. This fear of non-disclosure may lead families to distance themselves from family, friends and the wider community,[31],[32] with the result that they are forced to face these issues in isolation.

> *"It's lonely. Cancer on the other hand, had cachet – people sent me flowers. Nobody's ever sent me flowers for getting my sister out of jail."*

- 45% of caregivers of people with schizophrenia indicate they rarely or never get social support from family and friends.[33]
- Even when family members do choose to talk about their experiences and their needs, they may not be understood.

> *"My friends lost faith in my judgment. They wanted me to leave my husband because they thought I was being abused. I had to educate them about the illness."*

- Siblings of someone with a mental illness may isolate themselves from friends and community because of embarrassment,[34] and they may distance themselves from the family because of the stress and chaos. They may feel neglected as their parents focus on an ill brother or sister.
- Partner violence, conflict, low relationship satisfaction, and economic and legal vulnerability are common in families with substance use issues.[35]

IMPACT ON CAREER AND FINANCIAL SECURITY

Not unlike serious physical illnesses, mental health and addiction problems often have an impact on a family's employment and financial situation. This is the result of the additional stresses and time demands of caregiving, as well as the actual costs of supporting an individual who may not have financial independence. Together, these can have profound short-term and long-term effects on a family's financial security:

- 58% of informal / family caregivers in Canada pay out of pocket expenses to provide care to recipient family members, including transportation costs, medication costs and professional services.[36]

> *"I quit my job. Dealing with my husband's illness became a full-time job."*

- Women's careers are particularly affected. Women with mentally ill relatives are found to significantly reduce their hours when the ill member had difficulties with the daily living activities or when they have multiple mental illnesses.[37]
- Stress associated with mental illness or addiction can affect the productivity of employed family members.[38]

The story of one family member who shared her story during the Kirby / Keon Committee consultations

clearly points to the financial hardships faced by families:

> *"(W)hile we were very fortunate as a family to get access to this kind of support, it was at a tremendous family cost. It was a five hour drive from Ottawa for us to see our son. The emotional impact of having him ill that far away was tremendous."*

> *"Over the 14 months we drove 49,000 kilometres, lost 50 percent of our family income, closed a family business, and had $29,000 worth of out-of-pocket expenses"39*

Not all family members are affected equally by mental health and addiction problems. Instead, family members experience different types of stress based on their position in the family. Children of parents with mental health or addiction problems are particularly affected:[40]

- Children may take on a parenting role to an ill mother or father or a confidante role for a parent caring for an ill spouse/child.
- Children of alcoholic or drug-using parents exhibit increased rates of depression, anxiety disorders and other psychiatric issues,[41] while those of depressed mothers have high rates of anxiety, disruptive and depressive disorders that begin early, often continue into adulthood, and create impairment.[42]
- Children of alcoholic parents frequently experience chaotic parenting and poor quality home environments during significant developmental periods.[43,44] They may have behavioral and school difficulties, including negative self-concepts, fearfulness, loneliness, difficulties in concentrating, attendance, and work completion.[45] Children of addicted parents incur higher-than-average health care costs, and as a group, they are admitted more often to hospitals and have longer lengths of stay.[46]

Families of people with concurrent disorders (having an addiction as well as a mental health problem) face a situation where there are even fewer services and supports than there are for people with a mental illness or substance abuse problem alone. What is not recognized is that the co-occurrence of addiction and mental health problems is more common than not. This adds complexity to these problems, making it more confusing for families and consumers; and more challenging for clinicians to understand and respond effectively.[47] These families face more crises and have very few resources to meet their own needs. Services and supports that focus on one problem alone do not meet their needs.[48]

CONTRIBUTIONS OF FAMILIES

The social, emotional and psychological impact of a mental health and addiction problem on the family is profound. The enormous contribution families make is less obvious:

> *"Families are the single largest group of caregivers, often providing financial, emotional and social support, although their role generally goes unrecognized."*[49]

As pointed out by Senators Kirby and Keon, "[f]amilies are often the principle resource and the sole support available to individuals with mental illness and addiction. Because of the limited resources available to the hospital sector and the community, it is (families) who house, care, supervise and provide financial assistance..."[50] Approximately one-half to two-thirds of people with mental illness who are discharged from hospital return to their families.[51]

The important roles that family support can play in recovery from mental health and addiction problems are well documented.[52] These roles, and their value, have been recognized by professional groups and government bodies, many of which have called for increased family involvement in all areas of activity.[53]

A recent study, completed as part of Ontario's Community Mental Health Evaluation Initiative, found that 43% of families studied live with their ill relative, and of the remainder, 61% have either daily or weekly contact. Families are involved in a daily, ongoing supportive role whether or not their ill relative lives with them.[54]

Families who live with and care for relatives with either mental health or addiction problems may serve in a variety of roles. A recent survey commissioned by Health Canada[55] found that family members who provide care for those with a mental health problem may:

- Act as informal case managers, encouraging and supporting treatment; identifying and securing housing; and arranging for income assistance
- Provide crisis intervention
- Assist with system navigation
- Advocate on behalf of their ill relative
- Monitor symptoms and support adherence to treatment plans to lessen risk of relapse
- Provide housing, and assist with activities of daily living, including paying bills
- Maintain records of previous treatments, medications and hospitalizations
- Provide information on the context of a loved one's life, to assist professionals in understanding them as a whole person[56]

Numerous studies have shown that family involvement in these roles results in significant benefits – for both the individual and the health care system. Benefits include:

- Decreased rates of hospitalization and relapse
- Enhanced adherence to treatment choices
- Increased rates of recovery
- Decreased involvement with the criminal justice system
- Savings to the mental health and addiction systems[57]

FAMILIES SAVE THE SYSTEM MONEY

Families are not compensated for their work, nor are they reimbursed for the actual cost of providing care for their ill relatives. Health Canada found that "Caregivers are spending a considerable amount of money each month to provide care to someone diagnosed with a mental illness." This survey also concluded that 58% of informal/family caregivers pay out-of-pocket expenses. Of that number, over one quarter spent over $300 per month.[58]

Efforts to quantify the monetary value of the services provided by families are underway. At minimum, however, we know that when families provide care, costs of homecare providers and in-patient hospital stays are reduced.

Unlike professionals, who may provide many of the same services, families rarely receive recognition for their contribution. In 1991 the Canadian Mental Health Association (CMHA) compared the validation and support offered to professionals with that available to family caregivers.[59]

COMPARISON OF SUPPORT RECEIVED BY FAMILIES AND PROFESSIONALS IN THEIR ROLES AS CAREGIVERS[60]

Nature of Support	Support Received by Professional Caregivers	Support Received by Family Caregivers
Respite/Relief	Yes (through regular hours of work)	None
Recognition	Yes (through professional status)	None (but families are sometimes blamed for mental illness)
Training	Yes	Limited
Resources	Yes	None
Support from Colleagues	Yes	None
Remuneration	Yes	None (instead caregivers incur extra costs)

Little has changed. Thirteen years later CMHA concluded:

> *"Despite the importance of the role families play and the burden they carry, they receive almost no financial support. It is ironic that professional service providers, who provide care and support to people with mental illness, receive almost 100% of the mental health dollars, while families, who also provide care and support, receive virtually no financial resources."*[61]

WHAT FAMILIES NEED

1) SERVICES FOR FAMILIES: EDUCATING, SUPPORTING AND CARING FOR THE CAREGIVERS

"When you have a heart condition they give you a pamphlet – here's what we're going to do for you; here's what you should expect; here's what you should avoid; physical exercise is important. Nobody gave us a pamphlet."

Although families take on significant caregiving roles, they are usually ill-prepared for the challenges associated with this role. Family members often face mental health or addiction problems with little or no training or orientation. They may lack information regarding the problem, treatment, available resources, and the system itself. The complexity of the mental health and addiction systems make it challenging for consumers and families alike to navigate through the system and secure the appropriate help and resources.

"There's no support for navigating the system. God help you if you can't do that."

As a result family members are often left frustrated, not understanding what is happening to their relative, and not knowing how to support their relative through that process. Consumers and families facing concurrent mental health and addiction problems experience even greater frustrations as they are forced to navigate what are essentially two separate systems which treat these conditions separately.

Research shows that families who receive education about mental illness, and help to develop coping and problem solving skills, can help to ensure improved outcomes. One particularly important component of family education is that of mental health recovery and the role of families in the recovery process. When families learn basic recovery skills such as hope-instilling strategies, building on strengths, providing choices, and avoiding learned helplessness, much of the impact of mental illness can be ameliorated and recovery can be achieved. Recent research has demonstrated that, of the various combinations of treatments available, the best outcomes for people newly diagnosed with schizophrenia were realized when family education was added to a regimen of sustained medication and case management.[62]

The Kirby / Keon Committee recognized the "great amount of unpaid and recognized care and support" that family members provide and the importance of listening to family suggestions and needs. During the Committee hearings families spoke of their needs for:

- Better information and education
- Income support to cover expenses and lost income
- Peer support to allow family members an opportunity to share fears and frustrations and to learn coping skills from those with similar experiences
- Respite services to give caregivers a break from their responsibilities
- Access to information about their loved ones care and treatment to enable them to provide the best possible care for their family member[63]

"There are two sides to the role of the family – we can be so much help in our relative's recovery, but we need help ourselves."

2) PEER SUPPORT – FAMILIES HELPING FAMILIES

Families have needs that often go unrecognized. They are under stress and may themselves need emotional support and perhaps even treatment. Their loved one's illness can lead to substantial financial burden, careers can be interrupted, social networks may desert them due to stigma and discrimination, and they may be blamed for their loved one's mental illness or addiction. People who have "been there" understand all this and, in the context of self-help and mutual aid groups, provide a caring atmosphere where families can speak freely, exchange coping strategies and educate themselves about their loved one's illness or substance use problem – and about their own needs for support. After becoming members of self-help groups, they feel better able to navigate the mental health system and have reduced their tendency to blame themselves. They also have a better capacity to deal with stigma and discrimination.[64]

> *"I could not have gone through this without peer support."*

Research has shown that when families or family organizations have the resources to provide family-to-family educational programs, there are positive results: Increased empowerment, a decrease in perceived burden despite the fact that the actual burden stays the same, and improved self-care.[65] However, family-led educational programs remain scarce.[66]

Family members value the roles of self help/mutual aid organizations, which may include public education and awareness, one-to-one counselling and support, family case management and/or system navigation, crisis intervention and advocacy.[67] Family members affected by concurrent disorders also benefit from facilitated support groups and manuals and they report improvements in a number of dimensions, including caregiver burden and hopefulness.[68]

A recent evaluation of Ontario's family mental health initiatives concluded that self help/mutual aid organizations provide families with necessary support, education and advocacy, and that families benefit.[65] The evaluation also noted that:

> *"Families and consumers provide thousands of volunteer hours to help others. When the cost of this time is calculated, findings show … the Ministry's investment of about $300,000 in these self help groups is increased up to five-fold by families' volunteer investment of their time over a year."*[70]

The conclusion was clear:

> *"Although self-help and mutual aid organizations support large numbers of family members, they are an unacknowledged and under-funded arm of the mental health system."*[71]

There is an urgent need for increased support to family organizations. The Senate Committee's report, Out of the Shadows at Last, recommended that provinces and territories ensure that "existing and new consumer and family organizations be funded at an annualized and sustainable level."[72]

3) RECOGNITION AS PARTNERS IN CARE, REHABILITATION AND RECOVERY

Most people discharged from hospital following a psychiatric admission return home to their families.[73] Individuals with alcohol use disorders also typically maintain contact with loved ones.[74] Their relationships are often complex, demanding and intense.

> *"It took a long time before I found someone who would accept me as part of the support team."*

But families report that their perspectives, their observations and their opinions are rarely sought, and often discounted, by service providers. Their efforts to be actively involved, and to advocate on behalf of their ill relative, may be met with disinterest or suspicion. Worse still, some providers behave as if the family were responsible for the illness.[75]

> *"We were treated as if the family were to blame."*

Even professionals who are interested in supporting families express concern, perhaps unnecessarily, about violating personal privacy if they share information. A social worker who runs a successful family support program says:

> *"I still struggle with getting professionals to refer to my family support group. They cite privacy and confidentiality as reasons not to refer. If only they would take the time to unravel the "no," they would find that many consumers want their families to be involved."*

Families want to be an integral part of treatment and community rehabilitation teams as they are deeply concerned about the recovery of their loved one. However, research has shown that few consumers are asked by mental health providers for their permission to share health information with family members. Consumers' attitudes towards family members are more positive if professionals encourage the involvement of family in treatment and family members' satisfaction is directly related to receiving information from providers.[76] In a review of 70 studies using randomized trials, it was discovered that involving a spouse in the treatment of a loved one with depression had more positive outcomes than medical treatment alone.[77]

Families also contribute to the recovery of loved ones with substance abuse problems. Analyses across studies demonstrated the effectiveness of spouse and family involvement in treatment for alcoholism. In addition, therapies that enhance the functioning of the couple improve outcomes for the abusing partner. Helping the spouses of people with substance abuse problems who are unwilling to seek treatment has been shown to be highly beneficial in moving them towards a decision to get help.[78]

4) FAMILIES AS SYSTEM PARTNERS

Family members and family organizations are poised to be active participants in system planning. Families have seen first hand how the system works and know better than anyone that there is room for improvement. Families often act as advocates for their loved ones at the point of care (crises, hospitalization, referral to community services, social assistance and legal issues) and this advocacy equips them for participation in system planning, program development, implementation and evaluation, legislation critique, and mental health reform activities.

Many key Ontario policy documents have recognized the important role and contribution of families as system partners.

The Centre for Addiction and Mental Health, the Canadian Mental Health Association, Ontario and the Ontario Federation of Community Mental Health and Addiction Programs issued a joint statement regarding the critical success factors for mental health reform in Ontario. One important recommendation was the following:

> *"Consumers and families will be involved in all aspects of planning, decision-making, implementation and service delivery. "*[79]

In a joint submission in response to consultations regarding establishing Local Health Integration Networks (LHINs) in Ontario, these same partners called for the following mechanisms to ensure family involvement:

> *"Consumers and families must be at the centre of the transformation agenda and involved in all aspects of planning, decision-making, implementation and service delivery: If the transformed healthcare system is to become truly consumer-centred and able to improve the health of Ontarians, then consumers and families living with mental health and addiction needs must be integrally involved in the transformation of the system. Applied to the implementation of the LHINs, this principle means that (…) Consumer and family organizations*

must be invested in and supported so as to be able to make their voice heard. Furthermore, LHINs must ensure that consumers and families from diverse backgrounds and with diverse experiences are fully able to access and participate in mental health and addiction planning, decision-making, implementation and service delivery."[80]

Finally, families have been invaluable partners in research, including involvement in designing research, data collection and analysis, and the dissemination of findings. Involving families in research has been shown to lead to

- Improved research design
- Informed research questions
- Enhanced quality of data
- Broader knowledge translation activities[81]

RECOMMENDATIONS – BUILDING A FAMILY INCLUSIVE MENTAL HEALTH AND ADDICTION SYSTEM IN ONTARIO

The needs and contributions of families living with mental health and addiction problems must be addressed. The frequently overwhelming stress they experience requires that they have access to services and supports designed to answer their questions and respond to their concerns. The critical role they play demands that they be recognized as partners in the care of their loved ones. The valuable contribution they make to Ontario's health care system justifies significantly greater investment in family programs and services.

With that in mind, we call for increased recognition and support in the following four areas:

I. Enhancing services and support for families

II. Supporting family peer support and family organizations

III. Involving families as partners in care, rehabilitation and recovery

IV. Involving families as system partners

These recommendations acknowledge and build on the important work of family organizations across the province, including the Family Council: Empowerment for Families in Addictions and Mental Health, whose Family Centred Care Initiative was used as a model for recommendations in these four areas.

I. ENHANCING SERVICES AND SUPPORTS FOR FAMILIES

Families need improved access to information, education, counselling and sometimes respite services which can provide a break from their caregiving responsibilities:

- Whether provided by professionals, or by families themselves, accurate information can do much to allay fears, overcome misconceptions and address concerns.
- Education can help families develop successful coping strategies and enhance their contribution to the recovery of their loved one.
- Counselling can assist families in coming to terms with the implications of living with a loved one who has a serious mental health or addiction problem.
- Consumer programs and services such as employment or social recreation programs benefit consumers while providing families with brief respite.

WE RECOMMEND THAT:

The Ministry of Health and Long-Term Care:

1. Create a protected per capita funding envelope of new monies for family programs including respite services.

2. Develop data collection systems for use at the LHIN and provincial levels to capture the amount of funding being directed to family programs and initiatives.

Local Health Integration Networks (LHINs):

3. Ensure better access and availability for all consumers to support services such as social / recreational, education, training and employment programs which enhance consumer and family well-being.

4. Ensure all clinical addiction and mental health programs provide family education, support and counselling. All families should have access to general information about addiction, mental health and mental illness, treatment options and coping strategies.

5. Ensure a comprehensive, well-coordinated, easy-to-access and culturally competent range of family services and supports in every LHIN region for families affected by addiction or mental health problems.

6. Enhance collaboration among family programs and initiatives and other mental health and addiction service and support providers by convening, supporting and facilitating regional and local networks and alliances.

7. Increase the capacity of family organizations to review and inform evaluative information on service effectiveness.

Addiction and Mental Health Service Providers:

8. Provide in-service training to all staff, including direct service providers and administrative staff, to educate and sensitize staff so that they can work well with families and recognize their needs.

9. Ensure professional services such as family education, counselling or therapy are provided to all families who request support regardless of whether their family member is receiving services.

II. SUPPORTING FAMILY PEER SUPPORT AND FAMILY ORGANIZATIONS

It is accepted that no one is better equipped to provide support to families than someone who has experienced the trauma of a loved one's diagnosis or dealt with the fallout from a relative's substance abuse problem.

- The critical role of families in the mental health and addiction systems is obvious. Their need for enhanced support is clear, and the effectiveness of family self help/mutual aid programs has been demonstrated. And yet, there are few such programs, and those that do exist are starved for resources.
- Much of the stress of living with a serious mental health or addiction problem comes from the social stigma and discrimination still attached to those conditions, the lack of understanding on the part of the public and the resulting social exclusion. Health promotion and anti-stigma and discrimination programs must receive far greater emphasis than they do at present, if we are to address this issue.

WE RECOMMEND THAT:

The Ministry of Health and Long-Term Care:

10. Include in the Ministry policy framework provision for annualized and sustained funding for peer support and mutual aid organizations.

Local Health Integration Networks (LHINs):

11. Ensure equitable access to peer support and mutual aid for families in every LHIN and across ethno-cultural communities.

12. Encourage the development of new and innovative strategies (i.e. online support groups, chat rooms, etc.) for offering peer support and mutual aid to families.

Addiction and Mental Health Service Providers:

13. Facilitate the integration of family peer support and mutual aid within existing addiction and mental health programs through provision of in-kind supports such as use of office or meeting space for family support programs and initiatives.

14. Ensure staff members are knowledgeable and supportive of community resources for family peer support and mutual aid and that they can make appropriate referrals.

III. INVOLVING FAMILIES AS PARTNERS IN CARE, REHABILITATION AND RECOVERY

Families have valuable information and knowledge about their relatives. They also have expertise, acquired through sometimes painful experience. They know about approaches that work and those that do not. Consumers, service providers and families benefit greatly when family members are involved as full partners in the care and support of people with mental health and addiction problems.

Partnership has at least three critical components – communication, respect and collaboration.

- Families recognize the constraints imposed by Ontario's privacy legislation, but urge providers to re-examine internal policies to encourage and allow sharing as much information as possible within limits of the legislation.
- Respect requires that service providers recognize and value the unique contribution that family members can and do make. The family's strengths, expertise and contributions must be acknowledged.
- Collaboration demands an organizational culture that assumes that family members will be involved, and policies and practices that are conducive to their participation in all phases of the treatment, community rehabilitation and recovery process, wherever appropriate.

WE RECOMMEND THAT:

The Ministry of Health and Long-Term Care:

15. Develop a provincial policy framework on families, and working with families, within the addiction and mental health systems. The framework should recognize ethnocultural, socio-economic and religious diversity of families and their differing needs and experiences, and include a "cultural competence" component in the practice model of family support programs and in the accountability framework. Precedence has been set through the Ministry's "Program Policy Framework for Early Intervention in Psychosis" which identifies family education and support as one of seven key components for Early Intervention in Psychosis programs for Ontario.
16. Establish provincial standards to guide mental health and addiction practitioners in integrating families as members of the care team, while respecting the rights of consumers and clients to privacy and autonomous decision-making.

Local Health Integration Networks (LHINs):

17. Support and fund continuing education initiatives led by families for addiction and mental health service providers to help them learn how to work with families and understand their needs.

Addiction and Mental Health Service Providers:

18. Develop organizational policies and procedures which speak to the value of involving families as care providers and which outline practical strategies for involving families.
19. Develop core curriculum for working with families to be incorporated into accreditation training for mental health and addiction professionals, including family physicians and psychiatrists.

IV. INVOLVING FAMILIES AS SYSTEM PARTNERS

Ontario's health care system is currently undergoing a significant transformation. The development of the Local Health Integration Networks (LHINs) signals the government's intention to ensure that communities have significant input into the design and operation of local health services, and that the system itself is accountable, at the local level, to the

people it serves. The enabling legislation requires that the LHINs develop mechanisms for community engagement. It does not, however, identify families among the groups to be involved.

WE RECOMMEND THAT:

The Ministry of Health and Long-Term Care:

20. Formally recognize families as key stakeholders and include family representatives in the development of Ministry policy for the addiction and mental health sector.

Local Health Integration Networks (LHINs):

21. Formally recognize families as key stakeholders in the planning and evaluation of the addiction and mental health systems through the inclusion of family representatives on LHIN local advisory committees.

Addiction and Mental Health Service Providers:

22. Provide a voice for families in decision-making by including family representatives on mental health and addiction organizational boards and committees.

MOVING FORWARD

The need to recognize, involve and support families is not new. For almost 20 years, various Ontario policy documents have recognized the important role of families.[82] Most recently the Kirby / Keon Committee provided very strong acknowledgement of the role and importance of families in the mental and addiction system and called for provinces and territories to recognize this role through funding to support families.[83]

Despite this long-standing acknowledgement of families and the care they provide, the overall acceptance and implementation of family related services and supports has been slow. Professional services receive far and away the majority of mental health and substance abuse treatment dollars.[84] Verifiable estimates of the level of funding for family programs (treatment, support and self-help) are unavailable from the Ontario Ministry of Health and Long-Term Care. This lack of data is itself problematic and speaks to the need to more formally recognize the family sector.

Families need, and are beginning to demand, that the health care system respond to their concerns. Involving and supporting families will reap rewards for everyone:

- **Consumers**, who will benefit from the efforts of a team that works together on their behalf
- **Service providers**, who will find new partners for the demanding work they do
- **Families**, who will be empowered to actively support their loved ones with mental health or addiction problems

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"There's a gift in this. My sister has given me an understanding of the boundlessness of what it means to be human. From the depths of despair, she can fly with the angels."

Improving Ontario's mental health and addiction system requires the collective efforts and commitments of the Ontario Ministry of Health and Long-Term Care, the LHINs, service providers, consumers and families. It is time for families to be included as key stakeholders with a valuable role to play and with real needs that can no longer be ignored.

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APPENDIX A – THE FAMILY NARRATIVE

IN THE WORDS OF FAMILIES

The following are the stories of seven people whose family members have been diagnosed with serious mental health or addiction problems. Their passion, their wisdom, and generous spirit overflows in these stories and adds a profoundly human dimension to an issue that is, too often, neglected:

- My son was diagnosed with bipolar affective disorder in early adulthood. A graduate student with a promising future at the time of the diagnosis, he has managed, despite a number of relapses, to build a successful life and career.
- My husband experienced repeated episodes of what would eventually be identified as bipolar disorder. Our struggle to navigate the mental health system and to get appropriate treatment in the years prior to his diagnosis almost cost us our marriage, and created a major health crisis for me. I am now an articulate and committed advocate for family education and support.
- I am new to the system, with my husband having had his first manic episode mere months ago. I recently quit my job to help coordinate his treatment. Together we are learning to manage in this new reality.
- My sister has schizophrenia. The profound stigma attached to mental health issues in our cultural community, and the shame experienced by my family, prevented us from seeking treatment for many months. I wonder how much I can expect of my sister, and what the future will hold for us.
- I am new to Canada – simultaneously adjusting to the culture and the mental health system that supports my son. Recently diagnosed with schizophrenia, he receives treatment from the same organization that supports me in my efforts to adjust.
- Since age 17, I have been my sister's primary caregiver. In the past 30 years, I have been exposed to every aspect of Ontario's mental health and addiction system as my sister struggles with both a serious mental illness and a devastating addiction.
- I am a retired businessman whose ex-wife descended into alcoholism and despair. The pain of that experience, and my concern that my handling of it may have led my son to follow in his mother's path, is evident many years later.

These individuals shared their experiences, in some cases for the first time, in interviews with the author ranging from 50 minutes to 3 hours, in February and March of 2006. Although their stories are unique, there are common themes among them. The words are their own:

ANXIETY AND APPREHENSION ARE CONSTANT COMPANIONS

For someone with a mental health or addiction problem, and for their families, life can be chaotic and unpredictable. Symptoms may appear one day and abate the next. Behaviour that a week ago was unthinkable becomes "the new normal" the following week. Families may feel powerless to do anything other than worry:

"For the first eight months his life was in jeopardy all the time."

"If nothing awful happened in a day, I felt really lucky."

Even when the situation improves, a worried family member remains alert for indications of relapse:

"I keep looking for signs – He's been waking up at 3 AM this week – Is there something going on?"

"He's doing well now, but there's always that worry…"

That can lead, in turn, to an escalating cycle of distress:

"He knows that I'm worried about him, so he worries about my worrying."

And then, in moments of relative calm, there's time to think about the other implications of a relative's diagnosis:

"My sister was diagnosed at 19. I was 2 years younger and I knew there was a family connection – what was going to happen to me? It wasn't until I was in my 30s that I began to relax about it."

Not surprisingly, the presence of a serious mental health or addiction problem can have significant consequences for all family members. Research has shown that caregivers have higher rates of affective and anxiety disorders and are twice as likely as non-caregivers to use mental health services for their own problems. Spouses of problem drinkers report high rates of anxiety, depression and low self-esteem. Siblings of people whose schizophrenia creates behavioural disturbances display high levels of distress. Children of alcoholic or drug-using parents exhibit increased rates of depression, anxiety disorders and other psychiatric issues, while those of depressed mothers have high rates of anxiety, disruptive and depressive disorders that begin early, often continue into adulthood, and create impairment.

IF ONLY…

The vigilance required to cope with the uncertainty of the condition often results in families' feeling a heightened sense of responsibility for their ill relatives. They may convince themselves that they could have recognized the problem earlier and that they should have taken action:

"I sensed something was wrong. If only I'd told him not to go."

That 20/20 hindsight can lead to guilt and remorse:

"If I had understood the situation, I wouldn't have blamed my wife for her addiction. If she had felt more support than blame, maybe things would have turned out differently."

"I left my son alone with his mother a little too much. He had to handle a lot. He seemed okay, so I didn't pay much attention."

Family members may also deny themselves the right to normal, human responses:

"I feel guilty when I get angry with her."

IT FEELS LIKE NOTHING WILL EVER BE THE SAME AGAIN

The impact on families is far-reaching and profound:

"There's a long learning process for families – we move from knowing that there's something wrong, to acknowledging it, then to realizing that we have to deal with it somehow."

Parents, partners, siblings and children react, and cope, in different ways, at different stages of that process. What's certain, however, is that their lives are forever altered. The chronic stress that family members experience, along with the practical demands of caring for their relative, can impact their health, relationships, careers and financial situation:

"It isn't just that you're dealing with someone who's ill. The nature of this illness means that you're constantly traumatized. We suffer from all the symptoms of Post-Traumatic Stress Disorder."

"I lost a 30 year friendship. I leaned on them so much, they were overwhelmed."

"My sisters' diagnosis was the last straw for my parents' marriage."

"I quit my job. Dealing with my husband's illness became a full-time job."

Life events that are normally a cause for celebration become a source of stress and conflict.

"I had to take my daughter to buy her wedding dress. Her mother wasn't sober that day."

The sense of loss is unmistakable:

"You mourn the loss of everything that was, is, and could be – every potential that won't be realized."

And always, there's the feeling that someone else's needs must come first:

"You're absolutely besieged on every front. Taking care of yourself is the last thing you do."

Despite that, there is, for some families, a silver lining to this dark cloud. The same challenges that cause such stress can make family ties grow stronger. As they learn about recovery and understand their role in it, they feel empowered and supported. As they meet other families who share their experience, they find a new sense of community.

"This is a transformative journey."

"I've found a way to manage being overwhelmed every day. I have to make sure I'm catching my breath, and I've learned how to do that now."

"You become more sensitive and forgiving with other people."

THERE'S AN ELEPHANT IN THE ROOM

Most of us, when diagnosed with a significant health problem, seek support from family and friends. Often, they rally round to express concern and offer assistance, whether we ask for it or not. When a family member has a significant mental health or addiction problem, the response can be quite different. Stigma, misinformation, and a lack of understanding can mean that families and consumers face the most difficult battle of their lives in isolation:

"You're alone with this illness. Even if you want to talk about it, nobody else does."

For those who've also had a serious physical illness, the contrast is striking:

"It's lonely. Cancer, on the other hand, had cachet – people sent me flowers. Nobody's ever sent me flowers for getting my sister out of jail."

"We can put disabled kids on TV, but there's nothing 'sexy' about schizophrenia."

If, ultimately, families do choose to talk about their experience, they may not be understood:

"My friends lost faith in my judgment. They wanted me to leave my husband because they thought I was being abused. I had to educate them about the illness."

But education requires open discussion of a subject which, for many people, is still considered taboo:

"Stigma prevents my husband from revealing his condition. He could help people so much if he would go public."

"We need to help people with mental illness to talk about it."

"Let's have really honest conversations about psychosis. Let's stop whispering about it, and make it cocktail party conversation."

Those "honest conversations" could ease the burden experienced by families and help to ensure that people receive the support they need:

"Many people in my (cultural) community want to come here (to the resource centre), but they won't because of stigma. Please tell others that there is help available, and that they shouldn't be ashamed to accept it."

IT'S MORE GOOD LUCK THAN GOOD MANAGEMENT

Rational, well-coordinated service delivery systems help people in need to access the necessary resources, and to find their way around the system once inside. For those with most other health problems, that information is readily available and delivered automatically, in the first phase of their involvement with the system. For those who need mental heath and addiction services, the path is much less clear:

"When you have a heart condition they give you a pamphlet – 'here's what we're going to do for you; here's what you should expect; here's what you should avoid; physical exercise is important.' Nobody gave us a pamphlet."

"There's no support for navigating the system. God help you if you can't do that yourself."

Ontario's mental health and addiction systems boast a wide array of excellent resources, but families are often left to find them by chance, and only after numerous frustrating attempts:

"You have to be really persistent to find our (family support) program."

"Luckily, I was able to find a great doctor – eventually."

Once that "great doctor" or other useful resource has been located, policies and procedures may hinder, rather than help families in their search for support:

"The system only worked when people broke the rules for us. It's the personal power and empathy of the individual, rather than the system itself, that allows us to be successful."

WE'RE PART OF THE SOLUTION, NOT THE PROBLEM

Most people discharged from hospital following a psychiatric admission return home to their families. Individuals with alcohol use disorders also typically maintain contact with loved ones. Their relationships are often complex, demanding and intense:

"I've been a parent (to my sister) since I was 17 – and my job is forever."

Awareness of that enduring commitment can have a profound impact on other life decisions:

"I knew in my twenties that, if I was going to do this (care for my sister) it was going to be me and M. If I got married, he'd be marrying both of us. Remarkably, I found a partner who was willing to do just that. R. respects my sister. He's taught me how to deal with her, and still have a life of my own."

"We knew early on that we couldn't deal with this (husband's illness) and have children too."

The important roles that family support can play in recovery from mental health and addiction problems are well documented. Those roles, and their value, have been recognized by professional groups and government bodies, many of which have called for increased family involvement in all areas of activity.

And yet, despite that, families report that their perspectives, their observations and their opinions are rarely sought, and often discounted, by service providers. Their efforts to be actively involved, and to advocate on behalf of their ill relative, may be met with disinterest or suspicion:

"It took a long time before I found someone who would accept me as part of the support team."

"You fight the same battle over and over again."

Worse still, some providers behave as if the family were responsible for the illness:

"We were treated as if the family were to blame."

Given that response, concerned partners can begin to doubt their own perceptions and their assessments of the situation. If, as time unfolds, their concerns prove valid, their sense of relief is palpable:

"I've been vindicated. I no longer have to defend myself all the time (with my relative's service providers). If you're not really solid in your own sense of self, dealing with the mental heath system is a recipe for disaster."

"The best and most important vindication was from my husband, who said 'I'll always know my wife has my back.'"

Even enlightened professionals, who are interested in supporting families (and their numbers are increasing) express concern, perhaps unnecessarily, about violating personal privacy if they share information. A social worker who runs a successful family support program had this to say about her colleagues:

"I still struggle with getting professionals to refer to my family support group. They cite privacy and confidentiality as reasons not to refer. If only they would take the time to unravel the "no," they would find that many consumers want their families to be involved."

WE HAVE NEEDS TOO

Families contribute significantly to the care of people with mental health and addiction problems – often at considerable personal cost. When they seek support, though, it may not be available:

"We can help so much in our relative's recovery, but we need help ourselves."

"In a perfect world, there'd be someone to take care of us, too."

But this world isn't perfect. In a health care system with finite resources, staff must attend first to those in the most obvious distress:

"Nobody wants to hear my story. In terms of triage, my needs aren't a priority. I don't qualify as part of the crisis."

"Overburdened hospital staff may take advantage of families – expecting them to do a great deal. It sometimes feels as if family members have to get sick and become patients themselves."

There may also be another factor involved – a lack of understanding by health care providers that families have needs too:

"There's little recognition among mental health professionals that families are also in crisis."

"The most critical issue is lack of awareness of problems within the family. Even providers in the addiction sector think only about the addict."

Service providers who do understand the need, and commit to addressing it, may find themselves overwhelmed by the complexity and demands of that task, in a system designed for brief interventions:

"There's no such thing as a five-minute phone call with a distraught family member."

"This kind of illness needs a lot of time. The system isn't set up to allow for it."

In addition to support from health care professionals, families also need access to a range of other resources:

"If we had more information earlier, we wouldn't have had to suffer for so long."

"The more legitimate information you have, the better you can survive – I had to get it through my psychology courses at university."

"Families need training about how to respond to unacceptable behaviour – when to let go, when to draw a firm line – especially given that the ultimate goal is to help the person become independent."

"I couldn't have gone through this without peer support."

And – perhaps most important:

"Can somebody just acknowledge us?"

JUST REMEMBER THIS

The diagnosis of a significant mental health or addiction problem can be devastating for families – in and of itself. There is little that can be done to minimize the shock and concern that comes with realizing that a loved one has schizophrenia, or a serious substance abuse problem, or any other condition that will influence the course of their life. There is much that can and must be done to minimize the impact of that realization:

"There was so much unnecessary pain."

"It's tragic that families disintegrate when mental illnesses are treatable."

Families need, and are beginning to demand, that the health care system respond to their concerns:

"There's got to be somebody who is a believer, with a sense of hope, not just a provider of services."

And providers themselves have begun to understand:

"We have to instill hope – it's the cornerstone for recovery."

"The way we offer support will have to change. Thanks to the Internet, families are getting much more sophisticated."

That change, as challenging as it may be, will reap rewards for everyone: Service providers, who will find new partners for the demanding work they do; consumers, who will benefit from the efforts of a team that works together on their behalf; and families, who will be free to experience the joy, not just the pain, of life with someone who has a mental health or addiction problem:

"There's a gift in this. My sister has given me an understanding of the boundlessness of what it means to be human. From the depths of despair, she can fly with the angels."