Ontario Mental Health and Addictions Strategy
Consumer Partnerships Theme Paper

"Partner with people with lived experience to transform the MH&A system and establish new ways of working together"

Preface

The Challenge

Annually, one in every five Ontarians will develop a mental illness or addiction, and one in 10 will have a serious problem with gambling.

Most will have relatively mild symptoms that pass with time, a change in their situation or treatment. However, two to three of every 100 Ontarians will cope with a serious or complex mental illness or addiction throughout their lives.[1 2]

> Mental illnesses and addictions are serious health problems that cause great hardship for too many Ontarians and their families and friends.

Although many dedicated people work hard to provide mental health and addiction services, the current system is fragmented. People with a mental illness and/or addiction often struggle to find the services they need when they need them.

Ontario's Response

There is no health without mental health.

In 2008, the Government of Ontario made a commitment to strengthen mental health and addiction services – and to develop a comprehensive 10-year mental health and addiction strategy that would lead to better services for Ontarians. To fulfill that commitment, the Government established an Advisory Group of people with lived experience with mental illness and addictions, family members, service providers and researchers.

The Advisory Group identified five priorities or themes that would help make a real difference in the lives of people with mental illnesses and addictions:

1. Early identification and intervention
2. Consumer partnerships
3. System design
4. Strengthening the workforce
5. Healthy communities

The Advisory Group organized working groups to review the literature and discuss each theme. The working groups developed draft theme papers that explored the key issues and challenges as well as strategic priorities and opportunities. Theme group members looked for best practices, and for ideas to transform mental health and addiction services to meet needs.

The draft theme papers were used to develop a consultation paper -- *Every Door is the Right Door* – which set out a proposed vision, mission, goals, and principles to guide for Ontario's mental health and addiction strategy.

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[1] Kessler R.C & Zhao S., 1999.
[2] Ruggeri M, Leese M, Thronicroft G, Bisoffi, G, and Tansella M., 2000.

The consultation paper was released at the provincial Summit on Mental Health and Addictions in July 2009, and individuals and organizations were invited to respond. Between September and December 2009, a series of 65 roundtables were held with key groups across the province.

The theme working groups used the feedback from the consultation paper and the roundtables to refine their reports.

This paper is one in a series of five theme group papers. It focuses on Consumer Partnerships and examines ways to partner with people with lived experience of mental illness, problematic substance use and gambling to transform the mental health and addictions system.

Overarching Vision, Goals and Principles for Ontario's 10-Year Mental Health and Addiction Strategy

Vision

Every Ontarian enjoys good health and well-being, and Ontarians with mild to complex mental illness and/or addiction live and participate in welcoming, supportive communities

Goals

- Improve health and well-being for all Ontarians.
- Reduce incidence of mental illnesses and addictions.
- Identify mental illnesses and addictions early and intervene appropriately.
- Provide high quality, effective, integrated, culturally competent, person-directed services and supports for Ontarians with mild to complex symptoms of mental illnesses and/or addictions and their families.

Mission

Every door can be the right door for Ontarians with mental illnesses and addictions.

All doors in the mental health and addictions system and the broader health, children and youth, education, social services, housing, seniors' services, settlement services and justice systems lead to integrated, accessible, person-directed services and supports.

Services focus on the hopes and needs of people with mental illness and/or addictions, and engage them in their own health and care.

Principles

Respect. People with lived experience of a mental illness and/or addiction are valued and respected members of their communities. They are treated with dignity and have access to the information they need to make informed decisions about their own treatment and services. They are active members of their treatment and support team. Health and social services are provided in the environment the individual considers to be the least restrictive, intrusive and

stigmatizing. Communities and services are proactively engaged in activities designed to eliminate stigma and discrimination.

Diversity. Individuals are offered culturally competent services that meet the needs of a diverse population at all ages and stages of life.

Partnership and Collaboration. People with lived experience are essential partners in system design, policy development, and program and service provision. People with lived experience, families, family organizations, service providers, governments, and the community collaborate to raise awareness about mental health and addiction services and improve knowledge about mental illnesses and addictions. All levels of government and services collaborate to provide seamless, integrated, equitably funded care – and make every door the right door.

Healthy Development, Hope and Recovery. Individuals using mental health and addiction services feel hope and optimism about the future. They have real choice in the services they use, and a variety of options close to where they live. They receive the least intrusive services possible in the least intrusive setting, as well as flexible, individualized supports that involve their families, significant others, and communities when desired. They have opportunities for healthy development and recovery.

Harm Reduction. Individuals are supported regardless of where they are in their journey to reduce the health, economic, and social harms associated with mental illnesses, problematic substance use and harmful gambling.

Excellence and Innovation. The mental health and addictions system strives for excellence and encourages best practices and innovation. It provides an effective, efficient continuum of high quality care that is evidence-based and results-oriented.

Determinants of Health and Well-being. Mental and physical health and wellbeing are more than just the state of one's health. In addition to caring for mind and body, the system works to reduce or eliminate the underlying individual and social factors that contribute to mental illness and addiction

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Executive Summary

In recent years, the involvement of consumers of mental health and addiction services and people with lived experience of mental illness, problematic substance use and/or problematic gambling have become central to discussions of mental health and addictions sector reform in Ontario and beyond. It is increasingly recognized that consumers of mental health and addiction services and people with lived experience must be centrally involved in creating a system that is responsive to themselves, their families and communities. The focus of the Consumer Partnerships theme is to identify ways to partner with these essential colleagues and support successful ways of working together.

There are several key issues and challenges which impact this goal. Although from prevalence rates we can assume there are many people with lived experience in positions of leadership in the mental health and addictions service system, they are often not visible. Additionally, there is too often a failure to recognize the value of peer-based initiatives among mainstream service providers and policy makers. Stigma and discrimination are major barriers that prevent people to self-identify, or to access essential services and supports. Family members and other informal caregivers who play a primary role in the lives of consumers who are living with mental illness and/or problematic substance use and gambling are key stakeholders in the continuum of care, yet their needs are often overlooked. Harm reduction and recovery are core principles of person-directed approaches to care, yet they are interpreted and implemented inconsistently. Systemic barriers make participation in partnership, including (re)entering the workforce, a daunting challenge for many people with lived experience, particularly those living with serious mental illness, problematic substance use or gambling, and those who are multiply marginalized. And lastly, there is currently a lack of accountability in the system for the effective involvement of consumers and people with lived experience. These challenges must be addressed in order to enable effective partnership between service providers, people with lived experience of mental health and addictions, and the mental health and addictions system.

This paper identifies several strategic priorities for the 10-year mental health and addictions strategy. The first priority is that people with lived experience must be meaningfully involved at every level of the mental health and addictions system, from prevention, to system and service planning and design, to funding and provisioning, professional training, service delivery, outcome measurement, monitoring and evaluation, to treatment and care planning. This necessitates supporting diverse forms of partnership, including autonomous consumer-led programs and services, as well as enabling creative linkages and programs which build on the strengths of both community-based and mainstream services.

The second priority is that the mental health and addictions system adopt harm reduction and recovery as core philosophies of services so that people experiencing mental illness, problematic substance use and/or problematic gambling are able to determine their own route to and through recovery or treatment with appropriate support, as needed. Harm reduction and recovery are evidence-based approaches which seek to improve health outcomes, large and small, for people with lived experience and aim to improve their quality of life in all its aspects.

The third priority is that people experiencing mental illness, problematic substance use and/or problematic gambling have opportunities to be socially connected and maintain meaningful relationships. Social inclusion is a key determinant of health, and people with lived experience must be supported to have meaningful roles in their communities; however that is defined by the individual.

The fourth priority is that families and other informal caregivers are recognized for their roles in supporting the health and well being of people experiencing mental illness, problematic substance use and/or problematic gambling, and are regarded as key stakeholders in the system.

And the fifth priority is that stigma is addressed through widespread and multi-sector educational campaigns which incorporate the leadership of people with lived experience.

Achieving effective consumer partnership is an overarching goal for the 10-year mental health and addictions strategy, and will require the commitment of government and community stakeholders working together. In keeping with the slogan “nothing about us without us”, which captures the idea that no policy or decision should be made without the full participation of the people who are affected by that policy, it is vital that people with lived experience of mental illness, problematic substance use and gambling become centrally involved in creating a system that is responsive to themselves, their families and communities.

1.0 Introduction

Consumer Partnership: "nothing about us without us"

In recent years, consumer involvement has become central to the discussions of mental health and addictions sector reform, and is increasingly recognized as an essential component of an effective system of services and supports. Peer involvement in mental health, substance use and addictions services has been gradually increasing over the past two decades, however the increase is significantly less in the areas of substance use and addiction policy and treatment[3]. One notable exception is the proliferation of 12-step abstinence based programs, including alcoholics and narcotics anonymous, which have rapidly grown in size and influence over the past several decades. A recent estimate put AA membership at over 2 million worldwide[4]. Unfortunately, the voices of people with lived experience remain marginalized in many mainstream health services, and their knowledge and resources untapped.

Ontario is farther behind in promoting consumer involvement through health policies in comparison to other Canadian and international jurisdictions. Notably, Denmark, Switzerland, the Netherlands, Australia, New Zealand, Manitoba and British Columbia have taken up policy positions and shown progress in terms of increasing the involvement of people with lived experience in their mental health and addictions systems. In the United States, the New Freedom Commission on Mental Health of 2003 had consumer and family driven care as one of its five priorities, and some states, notably Washington, have mental health transformation goals which include the involvement of consumers in diverse areas of the system. However, promoting the involvement of people who use substances is noticeably less prominent than the involvement of mental health consumers in most of the above jurisdictions, although support for families and communities in regards to substance use and addiction is named in some[5].

It should be acknowledged that many people with lived experience and family members are already involved in the mental health and addictions system, as they are motivated to work in the field as a result of their personal experience. In addition, it is not always easy to identify who has lived experience either themselves or as a family member – mental illness, problematic substance use and gambling encompass a broad spectrum of experiences or degrees of severity, from mild or moderate health issues to extremely debilitating illness. People with lived experience may hold positions of influence at all levels of the health system - and indeed in all walks of life - but many remain undisclosed due

[3] Cheng and Smith, 2009
[4] Alcoholics Anonymous, 2009.
[5] Health System Planning and Research Branch, Ministry of Health & Long-Term Care, 2009.

to the stigma of living with a mental illness or addiction. The system must embrace a cultural shift which acknowledges the consumer as the "owner" of their own care and allows space for people with lived experience to have a formal voice in a way that respects individual capacity and choice to participate. The focus of the Consumer Partnerships theme is to identify ways to partner with people with lived experience to transform the mental health and addictions system and support successful ways of working together.

In keeping with the slogan "nothing about us without us", which captures the idea that no policy or decision should be made without the full participation of the people who are affected by that policy[6], it is vital that people with lived experience of mental illness, problematic substance use and gambling become centrally involved in creating a system that is responsive to themselves, their families and communities.

A Note on Language

Debate continues in mental illness and substance use communities surrounding the use of language, as there are currently no universally accepted terminologies. It is recognized that terms are interpreted differently and as such, the usage of the terms within this document serve the purpose of providing meaning to the Paper itself and are intended for use only within the context of the Paper. They are not intended as recommendations for broader application outside the context of this document. Please refer to the Glossary in Appendix 1 for working definitions of terms as they are used in this document.

Consumer Partnerships Vision, Goals and Principles

In addition to the overarching principles above, the Consumer Partnerships theme group identified some additional principles which have guided the work of this theme group.

Vision

The consumer partnerships theme group envisions an Ontario where consumers or people with lived experience, their families and informal caregivers are

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[6] This populist slogan has been adopted by many groups of people worldwide, particularly people with disabilities, to reflect the need for their active inclusion and participation in decisions that affect their lives. The Canadian HIV/AIDS Legal Network (2005) also published a document with this title in regards to the inclusion of people who use illegal drugs in public policy and programs.

included as full and equal partners in decision making about their own care and treatment, and in all aspects of the mental health and addictions system.

Consumer partnership recognizes the need to consider a person's ability to make specific decisions and desire for involvement at any given time.

Goals

True partnership with people with lived experience necessitates a cultural shift and a fundamentally different way of doing business from the system that is presently in place. The high level goals that will build towards achieving this transformation are:

- A comprehensive range of person-directed services, which put people with lived experience of mental illness, problematic substance use and gambling at the centre of decision-making about their own needs and care.
- Mental health and addiction services which are provided at a uniform level throughout society, by respectful, non-judgemental and compassionate workers, without discrimination to all who need them, regardless of location or setting.
- A system which is accountable to people with lived experience and values them as integral and expert partners in system design, governance, policy development, program and service provision, as well as decision making about their own care. Sustainable mechanisms are in place at all levels to facilitate their meaningful involvement and participation and gain their insights. This partnership also includes their families or caregivers, where appropriate.
- A system which is respectful of individual consumer choices and capacities, and supports participation in decision making at the level the consumer desires.
- Peer support, mutual aid, self-help and other programs and services that enhance the capacities, supports and empowerment of people with lived experience are considered an essential part of the mental health and addictions system, and their roles in care provision are clear and well articulated.
- Stigma and discrimination are decreased as consumers are empowered within the mental health and addictions system, and their voices are valued and heard.
- A system which recognizes that mental health issues and substance misuse can occur separately or concurrently, and treats them as such.

Principles

- Health as a right for everyone

- People with lived experience as full citizens
- Equity and social justice for all, regardless of mental health status, use of substances or gambling
- Involvement of family and community caregivers, when appropriate
- Dual foci on individual capacity building and systemic change

2.0 Key Issues and Challenges

Ontarians need to be actively engaged in their own care, treatment or recovery. For mental health and addiction services to be effective, people need to be able to set their own goals and make informed choices about the services and supports they want and need. While some mental health and addiction services may strive to be person-centred, the lived experience of people with mental illness, problematic substance use and gambling is not always valued or respected. Programs are often designed for the convenience or needs of service providers, rather than the needs of those who use the services.

Sometimes people are expected to follow a pre-set path through treatment programs without respect for individual differences. They may not be offered a range of evidence-based, culturally sensitive services, or supported in choosing the services they think are best for them.

Review of the evidence and input from the various community consultations has revealed the following themes, issues and challenges in regards to the current state of Consumer Partnerships.

2.1 There is insufficient visibility of people with lived experience in positions of leadership in the “mental health and addictions system”, and a failure to recognize the value and effectiveness of peer-run initiatives among mainstream mental health and addictions providers/policy makers.

There is a perception in the mainstream that peer or consumer-run initiatives are not “evidence based” services, and are not essential supports within the continuum of care. In 1991, Ontario provided an influx of support to Consumer Survivor Initiatives[7], and peer support worker roles were designated for the province’s Assertive Community Treatment Teams. However, aside from these programs the province has shown little overall movement towards deliberately

[7] CSIs are self-help groups, alternative businesses or support services run by and for people diagnosed with a mental illness.

promoting the growth of consumer or peer led services in the mental health and addictions sector.

Although peer led programs and supports often have anecdotal and program evaluation-level evidence supporting their effectiveness, these types of initiatives are less studied and there is a lack of mainstream scientific research supporting their success as a model of service delivery. A review[8] has recently been completed for the Ministry of Health and Long-Term Care which proposes the development of equitable funding and human resource strategies for peer run organizations, and the Mental Health Commission is funding a study which examines how to embed peer support in mental health systems across the country. Currently, these services tend to be marginalized within the mental health and addictions system. In order to increase representation of people with lived experience, there is need for the recognition of validity and efficacy of peer support, self-help and mutual aid, and support to develop a strong research and evidence base on consumer and peer-led initiatives. In addition, these services need to meet the same standards of quality as other types of services, and look to peer-reviewed and grey literature from other jurisdictions that might guide their work.

Although prevalence rates can lead us to assume that there are many people with lived experience in positions of leadership in the mental health and addictions service system, they are often not visible. Consumers or people with lived experience, their families, friends and communities have first hand knowledge of mental illness, problematic substance use and gambling. This knowledge is valuable, and it is an ethical and human rights imperative that people with lived experience be considered integral partners in creating a responsive mental health and addictions system[9]. This involvement must touch all levels of the system and span the following functional areas:

- Planning and design
- Funding and provisioning
- Operational delivery
- Professional training
- Measurement, monitoring, and evaluation

Effective and equal partnership may not happen easily within the current context of the mental health and addictions system; however it is still essential that we strive for it. There is a need to build the infrastructure to enable persons with lived experience to participate on equal footing with their professional peers[10].

[8] O'Hagan et. al., 2009
[9] Canadian HIV/AIDS Legal Network, 2005; Cheng and Smith, 2009
[10] O'Hagan, M., McKee, H., and Priest, R., 2009.

Not unlike other parts of the funded mental health and addictions system, particularly community-based organizations, peer and consumer-led organizations and programs have struggled with chronic instability for many years in Ontario. In order to build the sustainability and responsiveness of these unique, often community-based services, the following are required:

- Enough staff positions
- Competitive wages and benefits, including support for staff development
- Adequate facilities, meeting and program space
- Support for program growth to meet community demand
- Support for independent and grassroots organizations and initiatives as well as programs in larger institutions/organizations
- Sufficient levels of personal and professional support and supervision for staff

Sometimes, consumer-run services and supports do not conform to mainstream ways of providing services. For example, they may not operate within regular 9-to-5 business hours. Additional challenges exist for people with lived experience who are working as service providers since they often have dual roles in the organization and the community. For people doing peer work, these dual roles often mean having personal/professional boundaries that are more flexible[11] than the boundaries inherent in, for example, a traditional social worker/client relationship.

Capacity building is key to supporting the participation of people with lived experience at all levels of the system and eliminating both the perception and the reality of tokenism. While many consumers, disclosed or not, occupy both volunteer and paid roles in the system, others may need specific training, mentorship, and fair and adequate personal and financial support to be effective and competent in their roles[12]. For example, people with lived experience who are recruited to sit on a board of directors but do not have previous experience in this role may need board orientation and ongoing mentorship in order to effectively participate as members. In other cases, consumers who have been unemployed for a length of time may need support and training to (re)enter the workforce. At the same time, administrative, professional and support staff of agencies working in partnership with people with lived experience must be prepared to work in a partnership model. Workplace standards may have to be addressed and specific training may be required to facilitate a cultural shift towards greater inclusion.

Organizations that are interested in hiring people with lived experience as staff should consider the need for formal recruitment strategies, responsive hiring

[11] Strike et al, 2004; Toronto Harm Reduction Task Force, 2003
[12] Mason, 2006

policies, and formal structures for peer and non-peer staff to share information[13], not to mention adequate compensation and benefits as are granted to other workers. However, implementing hiring policies to increase the number of disclosed people with lived experience in the workforce presents some challenges. Asking potential employees to disclose their status as a person with lived experience may violate legislation related to human rights, labour standards and access to health information. That said, supporting and not discriminating against staff or volunteers who disclose current or past experience of mental health, substance or gambling is an obligation of the employer. These issues are complex and require fuller exploration.

A review of peer-based services and supports noted that there is a general consensus that they are promising practices but not yet truly evidence-based. However, the review identified six aspects that are common to successful peer support initiatives:

- They have articulated a clear philosophy and guiding principles which clarifies their focus and differentiates them from traditional support approaches
- they are operationally independent
- they have effective recruitment processes
- they provide credible training which is consistent with the role
- they have effective supervision structures
- they have a fully developed organizational structure[14].

Partnership models such as consumer/survivor initiatives, peer support and service delivery programs, and participatory action research are ways of sharing expertise and building the capacities and competencies of people with lived experience. People who have first-hand experience using services have special insight into how to best address their own needs and those of their peer communities. Peer-based interventions have shown positive health outcomes[15], and, peer support and consumer-run initiatives have been shown to reduce use of acute health services such as emergency rooms[16]. The creation, provision of resources for and continuing support for drug user groups is essential not only in terms of providing community support to deal with the unique challenges inherent in substance use and/or addiction, but also as valuable resources to offer crucial input to policy, program development, and service delivery[17].   All of these diverse forms of partnership with people with lived experience must grow rather than continue to be threatened.

[13] Gates and Akabas, 2007
[14] Macfarlane et al, 2009
[15] Canadian HIV/AIDS Legal Network, 2005; Cheng and Smith, 2009; Orme and Starkey, 1999; Street Health, 2007; Doughty and Tse, 2005; Orwin, 2008
[16] Forchuk, C. Et al, 2002; Nelson et al, 2006.
[17] Crofts et al, 1993

2.2 Stigma and discrimination are major barriers that prevent people who are struggling with mental illness, problematic substance use and gambling to self-identify and to access essential services and supports.

People with lived experience of mental illness, problematic substance use and gambling often encounter both discrimination and stigma in many places and at many levels – in health care, in the community, within the family, and at the workplace. Stigma and discrimination are often experienced on a very personal level, and many individuals state that the stigma associated with their health issue is more difficult to bear than the illness itself. Further, stigma is often internalized, and stigmatized people may lose faith in their own worth. Stigma and discrimination may prevent people from accessing or maintaining necessities such as housing, relationships, employment and health care. Although it is difficult to eliminate discrimination or discriminatory practices that harm a person or group, it may be less complex to address than stigma. Stigma is usually less tangible, and it is culturally learned and culturally pervasive.

Many other types of stigma and discrimination compound the stigmas associated with mental illness, substance use and gambling. For example, stigma and discrimination are experienced by people living with HIV/AIDS, people with disabilities, people who are newcomers to Canada, people from racialized groups, people who are not heterosexual or gender conforming, and people living in poverty. People with lived experience of mental illness and problematic substance use are disproportionately represented in Ontario's jails and justice system, and the stigma of having a criminal record compounds their experiences of discrimination and marginalization. These different layers of stigma can exacerbate barriers to accessing services or participating as equal partners or decision makers in the mental health and addictions system[18].

Successfully addressing stigma will require forthright and committed efforts to normalize the experience and challenges of people with mental illness, problematic substance use and gambling, and to address the biases of those who are perpetuating it, including service providers. The mental health and addictions strategy requires an equity and human rights lens to address inequality on an ongoing basis, explore ways to support marginalized communities to empower themselves, and provide peer-based, culturally appropriate services. Research has shown that adaptations of peer-based programs across cultures have yielded good results[19].

[18] Committee for Accessible AIDS Treatment, 2008; Canadian HIV/AIDS Legal Network, 2005; Canale, 2001
[19] Orwin, 2008

Eliminating discrimination is critical to combating stigma, self-stigma, and the social exclusion of individuals with mental illness and addictions[20]. In order to provide equitable treatment supports and services, it is necessary to address the impact of the multiple, intersecting forms of discrimination that people face. Supporting and enforcing existing anti-discrimination legislation such as the *Accessibility for Ontarians with Disabilities Act* and the *Ontario Human Rights Code* is one path to eliminating the stigma that plagues the lives of individuals with mental illnesses and addictions, however it is also necessary to address the fact that it is *people* who stigmatize others – policies and legislation will be ineffective unless it becomes socially and culturally unacceptable to discriminate or marginalize.

2.3 Family members and other informal caregivers and supports who play a primary role in the lives of people with lived experience are key stakeholders in the continuum of care.

The terms “family” and “informal caregiver” must be understood to refer broadly to a person’s biological and/or chosen social relationships that provide support and care, and the person experiencing mental illness, problematic substance use and/or gambling must be viewed in context as a citizen, a member of a community, and part of a family. These social entities, relationships and the mutual responsibilities inherent in them should be considered in the provision of care and treatment when it is appropriate.

There is a need to provide supports, including peer support, to family members and other informal caregivers. They often play a critical role in providing support to those who are living with mental illness, problematic substance use and gambling. They may also be coping with significant stress, grief, stigma and disruption of daily living as a result of the illness of their loved ones, yet their needs and contributions are often overlooked[21].

Families and other informal caregivers need access to information and education to enable them to effectively support their loved ones. In addition, in many families where an individual is coping with serious mental illness, problematic substance use or gambling, the caregivers themselves either have their own similar or related lived experiences, or they may become consumers of services in order to get the support they need to provide support in turn. In some communities across Ontario, family members of people with mental illness, problematic substance use and gambling have formed peer support groups to

[20] Ontario Human Rights Commission, 2009
[21] Canadian Mental Health Association, 2006

give and receive information and support. These groups are often supported by mental health services and organizations. Participation in these groups often helps to reduce anxiety by increasing understanding, diminishing isolation and providing assurance that other people have had similar experiences. Participants receive encouragement and suggestions for taking care of themselves as they support their family members. They also receive information about how to best assist their family members to manage their mental illness, problematic substance use or gambling.

It is also important to acknowledge that family does not always provide a safe and supportive network for people with lived experience, particularly for people with experience of problematic substance use. In some cases, the family may in fact have contributed to the trauma which is at the root of a person's illness. Some families have experienced multiple generations of trauma and abuse which increases the likelihood of developing mental illness and/or problematic substance use. In the case of Aboriginal communities in Canada, the devastating effect of colonization, carried out over generations including through the residential school system, created severe trauma for families who were forced apart. Aboriginal children were stripped of their language and culture, and many experienced sexual and physical abuse. The impact of this trauma can be seen today in many communities that struggle with great vulnerability to mental illness and problematic substance use.

In some cases, family may be the least safe place to turn to for support. The whole family may need access to support and should not be expected to be caregivers. To the best degree possible, the autonomy and wishes of the consumer must be respected regarding the activation of these relationships.

2.4 Harm reduction and recovery have emerged as core philosophies of people with lived experience and community mental health and addiction services.

Recovery has no single meaning or unified constituency, but it appears to have three major perspectives: as a personal journey, as a social process and along with harm reduction, as a driver to fundamentally transform the existing mental health and addictions system[22].

The use of the word recovery has had different historical meanings in mental health and in substance use or addictions treatment. In the context of mental health, the recovery and wellness approach places an emphasis on the whole person and the re-establishment of positive personal identity, with a focus on

[22] Macfarlane et al, 2009.

strengths and goals rather than defining people by their illness. Secondly, it places an emphasis on self-determination and self-management to attain personal fulfillment. This approach promotes recovery of meaningful life with or without a reduction of symptoms. Recovery also changes the relationship between clinicians and service users by moving away from the "expert/patient" paradigm towards the clinician being a "coach" or "partner" in the journey towards recovery, with the individual regaining control over their progress. It also places an emphasis on attaining meaningful social and occupational roles within the community, rather than in segregated services. And lastly, recovery defines successful outcomes not exclusively in terms of symptom reduction but also in terms of improvements to quality of life, such as having safe and healthy housing, education, employment and participation. For this reason, a mental health and addictions strategy must recognize the important role of non-health-funded community agencies and services in supporting recovery and wellness alongside traditional mental health and addictions services.

In the context of addictions or substance use, the term recovery has often been understood to be synonymous with abstinence. While abstinence-based approaches work for some people who have lived experience of problematic substance use or gambling, for others total abstinence is not realistic, or even desirable. Harm reduction is an approach that aims to provide a range of options to reduce the harmful effects of mind altering substances (including alcohol) and/or gambling without requiring abstinence. Although the term "harm reduction" is often recognized in reference to drug use, for example in providing new needles and equipment for safer injection of drugs, or training to prevent overdose deaths, it is an approach that is employed for many other types of health concerns – for example, using a seat belt when driving in a car, having a designated driver rather than drinking and driving, taking herbal supplements to reduce the toxicity of pharmacological medications, or using condoms to prevent transmission of sexually transmitted infections. Harm reduction can also be applied in the context of mental illness, for example in taking medications to reduce symptoms, having access to housing rather than sleeping outside or intervening early to help reduce the severity of mental illness. A harm reduction approach "meets people where they are", taking into account their wishes, their capacities and their ability to make choices given the context of their situation, culture or environment.

Practicing harm reduction in the context of drug use has taken many forms which have proven to have success[23]. Peer networking, peer education and outreach among people who use drugs have been shown to improve health outcomes and

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[23] Allman et al., 2006; Canadian AIDS Society and Canadian Harm Reduction Network, 2008; Coyle et al, 1998; Latkin, 1998.

reduce the harms and risks of drug use by enabling the sharing of health information and providing social support[24].

Although many mental health and addictions services state they are recovery and/or harm reduction oriented, interpretation of what this means varies greatly. In addition, tools and supports which enable recovery and harm reduction are not universally available to all people with lived experience of mental illness, problematic substance use and gambling. For example:

- People experiencing mental illnesses may find they have easier access to psychiatric medications than to therapy, counselling or peer support which may sustain their recovery process.
- Some programs to treat problematic substance use require abstinence, or being “completely drug free” in order to access them, sometimes even including abstinence from prescription medications such as methadone
- People who are incarcerated have little control over how they access services or supports, services are typically not equal to those provided outside, and they do not have access to materials such as safer injection equipment or condoms.

Recovery and harm reduction approaches to services for mental illness, problematic substance use and gambling are evidence-based best practices. In keeping with a person-directed approach to the 10-year mental health and addictions strategy, both recovery and harm reduction put decision making, control and responsibility for health and well being in the hands of consumers or people with lived experience, as appropriate, rather than in the hands of service providers. Incorporation of these philosophies and approaches is vital to developing a person-directed system of care which includes partnership with consumers and/or people with lived experience.

Finally, both the harm reduction and recovery philosophies and approaches regard addressing the determinants of health as essential, particularly but not exclusively poverty and housing. A person who is impoverished and malnourished or who lacks a secure place to live in dignity is unlikely to experience an appreciable improvement in her or his mental or emotional health, or a significant moderation of her or his use of substances.

2.5 Systemic barriers and lack of equity make participation in programs and (re)integration into the workforce a challenge for many people with lived experience of mental illness, problematic substance use and gambling.

[24] Allman et al, 2006

People with lived experience who wish to access services such as psychotherapy and peer support programs may have difficulty doing so because these programs are often not considered medically necessary, and are therefore not covered by health insurance, or are not eligible for transportation subsidies.

People with mental illnesses and/or addictions are disproportionately represented in jails and the courts. There is a need for alternatives to the criminal justice system, for example court diversion programs, for *both* mental health and addictions. In addition, people who are in jail have little to no access to mental health or addiction services and supports, and when they are discharged into the community they often face additional barriers to employment due to their criminal records.

People with lived experience who utilize income supports such as the Ontario Disability Support Program (ODSP) face difficulties with employment, as they may be forced to give up their benefits or income in order to participate in paid work. This can be a challenge for someone who is unsure if they are ready to enter the workforce full-time, or who worries about having recurring periods of illness even if they are currently feeling well.

Employers have a role to play in supporting people with mental illness and/or addictions to enter or reintegrate into the workforce. Firstly, they can help to ensure that people with lived experience working in the system are treated equitably with other staff[25]. They can also help to address the needs and challenges of people using income supports such as ODSP or Ontario Works[26]. Some ways to begin this work include creating organizational policies which help integrate persons with lived experience into programs and services, for example staff orientation, training, deployment, and mentoring processes[27].

2.6 There is a need for accountability in the system to demonstrate that people with lived experience and their families and communities are engaged and meaningfully involved.

People with lived experience of mental illness, problematic substance use and gambling are often marginalized and may have little access to the political or social power which ensures system accountability. If we are serious about partnership and inclusion of people with lived experience in the mental health and addictions system, there is a need to build requirements for consumer or peer involvement into funding proposals and program planning, monitoring and

[25] Provincial consumer consultation, 2009
[26] Ibid.
[27] Committee for Accessible AIDS Treatment, 2008

evaluation[28]. The people who are using services should be considered the most important people in the system, and organizations should be accountable to them for both service quality and outcomes, as well as transparent about their strategies and success in regards to consumer inclusion.

3.0 Strategic Priorities and Opportunities

The following strategic priorities articulate long-term goals for the strategy (10 years from now and beyond) through the lens of consumer partnership. The strategic opportunities suggest ways to achieve the priorities and shift the mental health and addictions system to put people with lived experience at the centre.

See Appendix 2 for a table which summarizes some suggested Goals and Outcomes from which success could be measured.

Priority 1: Consumers or people with lived experience are meaningfully involved at every level of the mental health and addictions system, and the system supports diverse forms of partnership including consumer-led programs and services.

If people with lived experience are to be meaningfully involved in the mental health and addictions system rather than treated as token stakeholders, they must be empowered and supported to take on leadership roles at every level of the system, as well as recognized for their current contributions.

This involvement must span the following areas:

- Prevention
- System, program and service planning and design
- Funding and provisioning
- Professional education and training
- Service delivery
- Outcome measurement, monitoring, and evaluation
- Treatment and care planning

Consumer empowerment and the enabling of equitable partnerships necessitate a shift in power relations between service providers and the people who access services. The mental health and addictions system must evolve to allow people with lived experience to perform role functions as service or care providers as well as service recipients, and provide resources to strengthen the capacities of and support for individuals, families and communities. The system must also

[28] Mason, 2006

recognize the roles that many people with lived experience currently play throughout the health system and beyond, whether or not they have disclosed their health issues or status.

Consumer partnership should include support for a range of organizational models, from peer support and outreach to independent consumer/survivor or peer-driven organizations and initiatives, and the involvement of people with lived experience in mainstream health organizations, including hospitals. Partnership must also take place in system governance at the Ministry of Health and Long-Term Care, with Local Health Integration Networks (LHINs), and in the broader system which includes professional education, the criminal justice system, and beyond.

To enable equitable partnership, the historical devaluing of consumer experience and knowledge must be addressed, and a cultural shift must take place in mental health and addiction agencies as well as within broader health and social services sectors. Consumer-led initiatives need to be sustained and supported as critical, evidence-based services, as well as recognized as key initiatives which enhance the capacities and competencies of persons with lived experience. The system must protect and ensure the long-term viability of person with lived experience-driven services and programs, putting them on equal footing and better integrating them with mainstream mental health and addictions services by providing appropriate infrastructure supports and encouraging the development of creative, mutually beneficial partnerships.

Strategic Opportunities:

- Establish policy direction, standards and guidelines to promote accountability at government, LHIN and organizational levels for partnership with and support for consumer-driven initiatives in both mental health and addictions
- Establish clear and equitable roles and develop capacity-building resources and mechanisms to ensure the participation of people with lived experience in the design, development and delivery of mental health and addiction services, supports and prevention activities
    - Put training and mentorship supports in place to develop the capacities and skills of people with lived experience
    - Provide provincial capacity-building resources to support peer and mainstream organization collectives and boards, Executive Directors, CEOs and managers on the inclusion of people with lived experience and build leadership within the sector
    - Develop policies in organizations and the workplace to foster and support the (re)integration of people with lived experience
    - Encourage the participation of people with lived experience in the training of healthcare and social work professionals

- Put a focus on providing resources to persons with lived experience so they can participate on an equal level:
    - Mandate that LHINs and service provider agencies provide reasonable compensation and supports to people with lived experience who volunteer their time, including but not limited to honoraria, childcare, and travel subsidies
    - Provide scholarships or educational supports to persons with lived experience who wish to (re)enter the workforce but are stopped due to lack of financial resources for appropriate training
    - Require that organizations build educational, wage and benefit supports for staff into their budgets
- Direct the LHINs to sustain and grow a range of programs and services which offer peer or consumer-based supports to people with lived experience and foster consumer self-determination
    - Ensure that programs include autonomous peer-driven and directed services and organizations
    - Explore infrastructure support options for peer-run programs and organizations, such as back-office integration
    - Support the development of peer-based services that are culture and language specific
    - Encourage creative partnerships between mainstream health organizations and peer-run programs and services
- Reinforce the validity and efficacy of peer support, self-help and mutual aid by enabling the development of research and evidence to strengthen these types of services and by requiring the inclusion of peer-based and community-based research in the mandate of provincially funded research organizations
- Generate new system measures and performance indicators to ensure the system is accountable for engaging consumers
- Implement credible service-user satisfaction surveys on a system-wide basis
    - Service-user satisfaction indicators should be incorporated into both service provider and system-level performance evaluation
    - Develop benchmarks for service-user satisfaction to be implemented by the LHINs, which will enable system, LHIN and agency level reporting and drive agency peer accountability and transparency
    - Treat service-user satisfaction as part of a Continuous Quality Improvement approach and the commitment to developing a learning system
- Implement standardized Peer Support Worker training programs on a system-wide basis to ensure that peer support workers are properly trained and are integral to the system of continuing and community care
    - Leverage existing resources and successful training materials, such as the Toronto Harm Reduction Task Force's "Peer Manual: a Guide for Peer Workers and Agencies" and training projects such as the Ontario Peer Development Initiative and the peer-driven harm reduction programs at

    - places such as the South Riverdale and Queen West Community Health Centres in Toronto.
    - Build roles for peer support workers into service team guidelines and standards following the example of the Assertive Community Treatment Team standards
- Develop mechanisms for transparency in costs and effectiveness to allow the consumer to make informed choices regarding their own care and treatment.

Examples of Promising Practices:

Vocational Training Programs and Associations
- Vocational training programs can provide seconded paid Peer Support Workers to inpatient hospital units, emergency departments or mental health agencies. Secondments may be linked to specific roles or programs such as case management, crisis intervention or supportive housing.
- The worker can provide a valuable link for consumers to information and resources. Evaluations of these types of services have found that consumers find significant value in having access to a peer support worker[29]
- The worker gains work experience and the role can assist with re-entry to the mainstream workforce.

Patient Councils
- Groups of hospital users who independently discuss the service provided by the hospital and put forward solutions for improving the patient experience.
- In both general and psychiatric hospitals, Patient Councils work in partnership with staff to provide education to consumer/survivors and others (families and staff) on the choices and resources available to them, as well as to make recommendations on hospital care.

Service User Satisfaction Surveys
- Service user satisfaction surveys capture service user feedback about service satisfaction and overall system performance
- Experience in other jurisdictions shows this is an effective way of changing the relationship between service users and service providers
- Evidence indicates that when service user satisfaction surveys are conducted by a third party, the information provided is a more accurate and reliable indication of user concerns

Organizational Development Programs
- These programs offer support to developing self-help, peer or consumer/survivor groups in the areas of non-profit management, organizational, board and leadership development.

[29] Brantford Vocational Training Association, 2009.

- Several regional networks exist in Ontario.

Drug User Networks and Unions

- Groups of former and current drug users who provide peer support and education to improve the lives of people who use illicit drugs. Activities may include some or all of the following:
  - Organizing social action in communities to advocate for drug users' rights and issues such as access to health care and harm reduction materials.
  - Promotion of local, regional, and national harm-reduction education and interventions, and working to ensure that drug users have a voice in the creation of programs and policies designed to serve them.
  - Coordinating peer support groups for specific populations such as people on methadone, women, or people who use specific substances such as crack or crystal methamphetamine, or provide peer harm reduction and outreach.
  - Providing direct services and education to people who use drugs

Priority 2: Mental Health and addiction service and support providers implement harm reduction, wellness and recovery as core philosophies so that people with lived experience of mental illness, problematic substance use and gambling are able to determine their own route to recovery or treatment with appropriate supports

A truly person-directed, consumer-centred system is one where service users are able to take control of their own healthcare and make decisions for themselves, wherever possible. Such a system recognizes individual choice and capacity, in consideration of a person's ability to make specific decisions and his/her desire for involvement in decision making at any given time. People should be able to choose from a range of care and support services that enhance their quality of life and help them achieve their goals. Through enhancing self-determination, care moves away from something which is done *to* service users by the system towards a system of support built by people with lived experience and their advocates to help them achieve their goals and aspirations.

We envision a system where success is judged by whether quality of life improves for those with mental illness, and/or whose substance use and/or gambling are problematic. We envision a system which provides for equitable access to primary care for people with lived experience, where physical and mental health are given joint consideration in primary care settings, and where the interdependency of physical and mental health is explored as a matter of course. A commitment to a recovery and harm reduction-oriented system by mental health and addiction providers will ensure a flexible and holistic approach to care that delivers on quality-of-life outcomes.

Harm reduction and recovery approaches acknowledge the social and environmental contexts in which people with lived experience exist, and enable them to identify their own needs. Recovery and harm reduction form a foundation for the provision of services that are responsive to individual choices and capacities. We envision a system where mental health and addiction treatment, service and support providers are empowered to transform their services and supports so that they embody recovery and harm reduction as core philosophies, and where tools to support harm reduction and recovery are widely available to all people living with mental illnesses, problematic substance use and gambling.

Strategic Opportunities:

- Create Ministry of Health policy to mandate a person-directed approach to the delivery of mental health and addiction treatment, services and supports which is inclusive of recovery, wellness and harm reduction.
  - Align services to people's needs and preferences, take into consideration an individuals' unique circumstances and be sensitive to all aspects of diversity
  - Define harm reduction and recovery holistically, to include biological, psychological, social and spiritual components and mandate that providers adopt these two approaches as core philosophies
- Mandate through LHINs that mental health and addiction service providers create plans to involve individuals in creating their treatment or support plans and are provided with the information and support required to make appropriate decisions. Treatment or service plans should:
  - Provide several options including a combination of medical, psychological and social interventions, community and mental health resources, and social interventions.
  - Be focused on helping individuals achieve good quality of life.
  - Address the specific and unique needs of people, including the social determinants of health (e.g. employment, housing status, income).
- Enact a consumer/persons with lived experience Bill of Rights for mental health and addiction services and supports
  - Identify that consumers/persons with lived experience cannot be discriminated against based on one's path of treatment or recovery
  - Identify consumers as "customers" of mental health and addictions services and owners of their own care
  - Acknowledge that needs change over time, and that people with lived experience have the right to move in and out of the system and seek out supports as they require
- Address exclusionary criteria between mental health and addictions services to ensure people with current lived experience of mental health, problematic substance use and gambling can address their full set of needs

  - Review and eliminate, as appropriate, eligibility criteria that prevent persons with lived experience from accessing specialized services such as detoxification treatment
  - Develop concurrence capacity throughout the mental health and addictions system through cross-sector training on the relationship between mental health, substance use and gambling
  - Take a three pronged approach which addresses the following levels:
    - Service organization – look at the basis for organizing specialized mental health, problematic substance use and gambling services to find ways of better integrating and accessing all three sets of services
    - System performance – determine appropriate indicators to track local system performance in terms of creating greater concurrence between specialized mental health and addiction services
    - Capacity building – determine what is required to enable the implementation of best practices at all three levels
- Ensure health outcome indicators and Ministry system performance measures include quality of life measures
- Include training on harm reduction and recovery approaches in college and university-level professional training programs
- Provide training and education for primary care practitioners through professional colleges and associations (e.g. College of Physicians and Surgeons of Ontario, the Registered Nurses Association of Ontario, the College of Psychologists, the Ontario College of Social Workers and Social Service Workers, etc), as well as to criminal justice personnel on mental health and addictions, with a focus on:
  - Ensuring that primary care providers can help individuals and their families/supports make informed decisions about treatment.
  - Building capacity within primary care to support people to self-manage their conditions.

Examples of Promising Practices:

Peer-Led Harm Reduction Programs

- These programs are often housed in mainstream health organizations such as community health centres.
- Drug users have an integral part in program design, implementation and evaluation, and active illicit drug users form a significant proportion of the staff team and the program advisory board or committee.
- Programs may deliver services such as needle exchange through fixed site, mobile delivery and satellite sites, and are often accessible 7 days per week, 24 hours per day to accommodate the needs of service users rather than those of staff.
- Drop-in programs which target specific populations of substance users, for example, crack users, can help to increase communication with and among

them, build their capacities to develop and implement peer-led, substance-specific harm reduction strategies; and improve access to physical and mental health services for the population.
- Participants in these programs have reported improved sense of self-worth, greater knowledge of their substance of choice and safer drug use practices, increased sense of community, a reduction in drug use, and a more positive outlook on life[30].

Consumer/Survivor Initiatives (CSIs)
- CSIs are run by and for people with mental illnesses and/or those who have received mental health services.
- CSIs operate from an inclusive recovery based approach which aims to empower consumer/survivors. Some CSIs provide services such as peer support, while others are alternative businesses and provide employment and training to consumers.
- Research on CSIs has demonstrated that consumers who are involved in CSIs spend less time in hospital, use fewer crisis services, and are more socially connected[31].

Bills of Rights
- A Bill of Rights is a formal statement of the rights of a specific group of people
- Client or Service User Bills of Rights have been created in some organizations to promote mutual respect and articulate what a person can expect or is entitled to when accessing services at the agency.
- Examples of rights which may be articulated in a client Bill of Rights include the right to be treated with respect, the right to privacy, the right to be free from harm, the right to informed decision making and consent, and the right to make a complaint.

Priority 3: People with mental illness or addictions are socially connected and situated in a network of caring relationships.

One of the key determinants of health, including mental health, is social inclusion. We envision a continuum of services and supports, in the health system as well as the broader community, which helps Ontarians experiencing mental illness, problematic substance use or gambling to form and sustain meaningful social and occupational relationships within the community.

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[30] Street Health Crack Users Project, 2007
[31] Canadian Mental Health Association, Centre for Addiction and Mental Health, Ontario Peer Development Initiative, and the Ontario Federation of Community Mental Health and Addiction Programs, 2005.

Sectors which must be engaged in accomplishing this goal include health, community and social services, education, settlement services, children and youth services, health promotion, and housing.

Strategic Opportunities:

- Direct funding through the LHINs for peer support and peer-based recreational programs as a way to reduce the social isolation experienced by many people living with mental illness and/or addictions.
- Provide training to service providers in diverse sectors including education, correctional services, police, health and social services to implement peer to peer programs. Many population groups, such as youth, are more likely to speak with friends about mental health concerns than with mental health professionals[32].
- Develop a toolkit to provide resources to service providers in diverse areas and roles such as schools and social services to increase recognition of the signs of mental illness and problematic substance use and gambling, and build the competencies to intervene and offer support to individuals and families.
- Establish community-based services which support community integration (e.g. transitional supports such educational tutors, employment support, career planning, etc.) and ensure they are widely available through community hubs such as community health centres and municipal community centres.
- Support the development of organization-level programs to mentor people transitioning from peer-led roles and organizations into mainstream organizations.

Examples of Promising Practices:

Drug-Related Self Help Projects

- Interactive websites providing up-to-date information about such things as addictive substances, drug interactions, harmful additives, health alerts, etc.
- National and international e-groups where people can exchange information about bio-psycho-social-political nature of drugs and drug laws/policies, with a wide variety of people, including academic researchers, medical personnel (including some physicians) and street level or club-based drug users, and can develop strategic networks.
- E-groups addressing specific substances, such as party drugs or crack
- Informal – and sometimes formalized - harm reduction supply distribution projects to reach people in remote areas or who are unwilling or unable to access existing services.
- Informal support groups for people who have lost children to drug overdose

[32] Kelly et al, 2007

Interactive Websites

- Websites can offer anonymous spaces for people with lived experience to interact with each other, health professionals and access accurate information on mental health, substance use and gambling.
- Research shows that the internet is the first place many adults and youth go to for health information
- Use of the internet allows broad access to people living in remote communities and allows them to connect to or ask questions of peers who share common experiences.
- Facebook, Twitter and other means of electronic social networking are creating new communities where people of all ages connect in a timely manner regarding ideas, experiences or issues, including issues of drug use
- Live chat rooms and online counselling are possible.

Mental Health Self Help Projects

- Self help projects include programs where individuals can create their own "recovery plans," including monitoring their mood levels, quality of life and setting goals for change, with help from a peer support practitioner.
- Projects may provide access to peer support networks, resource and activities which provide a safe environment for people with mental illness.
- Tools of self-help and peer support improve mental health and well being by increasing awareness of mental health issues, raising awareness in regards to the positive contributions made by consumers, acknowledging that the determinants of health impact the well-being of consumers, and that their lives need to be viewed in a broader and dynamic context.

Population-Specific Peer Mentorship and Capacity-Building Networks

- Peer mentorship networks may be sponsored by organizations such as community health centres to offer training and formalized peer mentorship opportunities for people with lived experience who are from specific communities, such as youth or newcomers to Canada.
- These networks or programs place high value on involving people with lived experience in all aspects of their work, from offering training to service providers on working with specific populations, to involving peers in research projects specific to the population's experiences and needs.

Priority 4: Families and other informal caregivers are recognized for their roles in supporting the health and well being of people with mental illness, problematic substance use and gambling, and are treated as key stakeholders in the system.

Family and informal caregivers often bear the burden of care and support for Ontarians who are living with mental illness or addiction, yet support and recognition of the role of these key stakeholders is often lacking. Family, friends and other informal caregivers and supports must be considered integral partners in creating a responsive mental health and addictions system. The meaningful involvement of family, like consumers themselves, necessitates inclusion in all aspects of system and service design, delivery and evaluation, where appropriate. In addition, supports, including peer support, must be readily available to family members, friends and other informal caregivers.

Strategic Opportunities:

- Provide resources through the LHINs to support peer initiatives for families of people who have mental illnesses, problematic substance use and gambling
- Provide education and information at the organizational level to help individuals and their families make informed choices, change their approach to decision making, and build relationship and engagement skills.
- Enhance public education on mental health, substance use and gambling to:
  - Address stigma by challenging stereotypes and increasing understanding of mental illness, problematic substance use and gambling
  - Support prevention and identification, including self-identification, and provide information on how to access the system
  - Teach advocacy skills for consumers, family and informal caregivers

Examples of Promising Practices:

Family Education and Support Programs

- Ensure access to a family resource centre with volunteers who provide informal emotional support, understanding, education, coping strategies, and opportunities to meet with other family members.
- Involve families in client care, develop and improve professional services for families, and support families to help each other
- Ensure access to structured education sessions on recovery and mental health
- Ensure access to written information and referrals to community resources

Family Self-Help Support Groups

- Provide support to parents, partners and siblings who are caring for an individual struggling with a specific type of mental illness, problematic substance use or gambling
- Provide an opportunity for families to feel less isolated, to have a better understanding of what it's like to live with a specific mental health or addiction issue, to improve their coping strategies, and to be less isolated and feel supported by sharing their feelings and experiences in a non-judgemental environment.

- Provide peer mentorship between experienced family members and those who are new to the mental health and addictions system

Priority 5: Stigma is addressed through widespread educational campaigns which incorporate the leadership of consumers/people with lived experience

Stigma has been identified as one of the major barriers to disclosing one has a mental illness, substance use or gambling problem. Stigma is also a major barrier to prevention of mental illness, problematic substance use and gambling, access to treatment, services and supports, and to social determinants of health such as housing, employment, and social connectedness.

Peer-based programs, and the increased visibility of people with lived experience of mental illness, problematic substance use and gambling, help to combat stigma. In addition, health care practitioners and other types of service providers need to address their own stigma, beliefs and values which frequently affect their professional relationships with people with lived experience and negatively impact their ability to provide effective and non-discriminatory services.

Strategic Opportunities:

- Enhance public education at a provincial level on mental health, problematic substance use and gambling to:
  - Address stigma in all levels of society and the mental health and addictions system
  - Support identification (including self-identification) and how to access the system
  - Teach advocacy, resiliency and assertiveness skills for consumers.
- Strengthen and enhance existing school-based curriculum on mental illness, substance use and gambling which targets youth
  - Promote the use of existing school-based teaching tools such as the Canadian Mental Health Association and the Centre for Addiction and Mental Health lesson plans
  - Incorporate roles and leadership of consumers/people with lived experience into curriculum design and delivery
- Partner with people with lived experience, the Mental Health Commission of Canada and the Canadian Centre for Substance Abuse to build on their existing campaigns to address stigma and discrimination
  - Recognize that the anti-stigma and discrimination campaign is a long-term one which will span the duration of the 10-year strategy, that it is necessary to collaborate across diverse sectors for success on this goal, and that it requires political leadership

- Target the elimination of stigma and discrimination in treatment settings and in service-provider workplaces, as well as in the general population
- Promote the necessary behavioural and attitudinal changes that are required to eliminate stigma and discrimination as a barrier to service access
- Position Ontario as a catalyst for collaboration and as the province of "integration and action" – across mental health and problematic substance use and gambling
- Ensure the strategy is inclusive of the diverse communities affected by mental illness and problematic substance use and gambling

Examples of Promising Practices:

Consumer and Family Speakers Bureaus

- People with lived experience are trained to do public speaking about their personal experience with mental illness, problematic substance use and gambling. By sharing their personal stories, they can help demystify mental illness and addiction, promote acceptance and combat stigma, and advocate for essential needs such as safe and affordable housing.
- Speaking publicly can be an empowering experience for people and provide an opportunity to gain confidence and achieve a greater sense of self-worth and participation.
- Note that rarely are people who successfully control their substance use or practice harm reduction afforded the opportunity to speak publicly about their experiences, since abstinence is considered the "gold standard" of success. This limits the pool of people with lived experience of drug use to a select minority and enables the imposition of pathology on people whose use of substances or whose gambling is not problematic to them, their families or their communities.

Conclusion

In recent years, consumer involvement has become central to the discussions of mental health and addictions sector reform, and is increasingly recognized as an essential component of an effective system of services and supports. Peer involvement in mental health, substance use and addictions services has been gradually increasing over the past two decades, but we need to do more.

Ontario has an opportunity with the 10-year mental health and addictions strategy to show leadership by shifting the mental health and addictions system towards greater involvement of people with lived experience at every level, as well as within other sectors that touch the lives of consumers. By creating diverse opportunities for involvement, formally embracing recovery, wellness and

harm reduction approaches, creating opportunities for meaningful community and social engagement, addressing the needs of families and other caregivers, and boldly challenging stigma, the strategy can take steps towards effective inclusion, and begin to shift some of the current inequities between consumers, service providers and decision makers and provide more effective services.

It is our hope that the 10-year mental health and addictions strategy will embrace the meaning behind “nothing about us without us”, and articulate a strong vision for a mental health and addictions system where people with lived experience of mental illness, problematic substance use and gambling are centrally involved in creating a system that is responsive to themselves, their families and communities.

APPENDIX 1: Glossary

Addictions: The term addiction is most commonly used to refer to the problematic use of alcohol and other drugs. Individuals also engage in other potentially addictive behaviours such as gambling, internet gaming, shopping, etc. For the purposes of this report, addiction is defined as chronic dependence, which is use (or behaviour) that has become habitual and compulsive despite negative health and social impacts (BC Ministry of Health Services, 2004).

The behaviours of primary focus are the use of psychoactive substances (alcohol and other drugs), and gambling. It is important to note that these behaviours occur along a continuum and do not always result in addiction or harm.
The spectrum of psychoactive substance use, as outlined below, also applies to other behaviours such as gambling:

- Beneficial use, which has positive health or social impacts (e.g., medical psycho- pharmaceuticals, coffee to increase alertness, etc.)
- Casual/non-problematic use, which is recreational or other use that has negligible health or social impacts
- Problematic use, which is use that begins to have negative consequences for individuals, friends/family, or society (e.g., impaired driving; binge consumption; harmful ways in which drugs are taken)
- Chronic dependence, which is use that has become habitual and compulsive despite negative health and social impacts. (BC Ministry of Health Services, 2004)

Concurrent disorders: applies to people who have been diagnosed with both a mental illness and an addiction.

Consumer, Consumer/Survivor, and Person with Lived Experience:
The term "consumer" or "consumer/survivor" has been used to self-identify by some service users, particularly in the mental health field, in place of terms such as "patient" or "client" which some deem problematic. The term "persons with lived experience" or "people with lived experience" is used throughout this report, in addition to the term "consumer", to describe those who have previously lived, or are currently living, with mental illness, problematic substance use or gambling with the acknowledgement that there are a variety of terms people use to self-identify, and that alternate terms may be preferred to describe one's self or experiences. It is also recognized that the "person" may refer to the "family" or "parents" with lived experience in some cases.

Discrimination: treatment or consideration of, or making a distinction in favor of or against, a person or thing based on the group, class, or category to which that

person or thing belongs rather than on individual merit. The Ontario Human Rights Commission defines discrimination as “unfair treatment due to a person’s identity, such as race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, marital status, family status or disability (OHRC, 2006). “

Dual diagnosis: applies to people diagnosed with a developmental disability and a serious mental illness.

Family: The term “family” is used in this document to describe any person who is identified as such by a person with lived experience of mental illness, problematic substance use or gambling. In the case of children, parents or legal guardians are included in the definition of “family”; however, others such as friends may also be included in the definition of family.

Harm Reduction: “Harm reduction” is both a philosophy and a set of practices that are pragmatic, evidence-based, and rooted in the intention to reduce harm. Harm reduction strategies embrace a long-term view of intervention and change, and place an emphasis on immediate, achievable and protective approaches to positive change.

In the context of substance use, harm reduction:

- Recognises that not everyone who uses drugs is addicted to them.
- Encourages and supports the incorporation of people with lived experience into all aspects of service delivery, from planning through evaluation.
- Recognises the expertises of people who use substances and people who provide services to them are tangible and complementary
- Provides services without discrimination, prejudice or negative judgment, and ensures that the quality of those services is not compromised by discrimination, prejudice or negative judgment.
- Acknowledges that people have a hierarchy of goals, and places its immediate focus is on pro-actively engaging individuals, groups and communities in addressing their basic, most pressing needs before engaging them in dealing with the things which society has chosen to criminalise, demonise or ignore.
- Construes health in a holistic manner and endeavours to address the social and economic determinants of health as outlined in the Ottawa Charter. Thus, it is situated within the framework of health promotion.
- Is grounded in the ethical values of social justice, and holds that everyone has the right to health and the right to receive health services, whether or not they are using a substance, licit or illicit.

Health Promotion: the process of enabling people to increase control over and to improve their health (WHO, 1986).

Mental Health: according to the WHO there is no "official" definition of mental health. However, most experts agree that mental health and the absence of mental illness is not the same thing; the absence of a recognized mental disorder is not the only indicator for mental health. Therefore, mental health can be understood as a resource that:

- enables individuals and communities to control their subjective well-being and to cope with adversity and change
- supports meaningful and inclusive participation in social environments.

Mental Health and Addictions System: The term "mental health and addictions system" is used throughout this report to refer to specialized health treatment, services and supports for people with mental illness, problematic substance use and gambling. However, people with mental health or addiction issues may also interact with many other general health, social and community based services, including primary care, long-term care, home care, income support, police, justice and corrections, housing, and schools.

Person-Directed: This approach values and supports active participation in decision making on the part of persons with lived experience, wherever possible, while recognizing the need to consider a person's ability to make specific decisions and desire for involvement at any given time. It is an approach that is mutually respectful and collaborative between providers and people with lived experience.

Recovery: There is significant divergence around the word recovery, and its interpretation differs among many groups. In this paper, we endorse a broad vision of recovery that involves a process of restoring or developing a positive and meaningful sense of identity apart from one's condition, and a meaningful sense of belonging while rebuilding a life despite or within the limitations imposed by that condition.

A wellness and recovery oriented system of care identifies and builds upon each individual's assets, strengths, and areas of health and competence to support achieving a sense of mastery over his or her condition while regaining a meaningful and constructive sense of membership in the broader community.

Serious Mental Illness: The three categories used to identify people with serious mental illness are: disability, anticipated duration and/or current duration, and diagnoses. The critical dimension is the extent of disability and serious risk of harm to themselves or others, related to a diagnosable disorder.

- Disability: Refers to the fact that some individuals lack the ability to perform basic living skills such as eating, bathing, or dressing; maintaining a

household, managing money, getting around the community and appropriate use of medication; and functioning in social, family and vocational-educational contexts.

- Anticipated Duration/Current Duration: Evidence may indicate that a person's problem may be ongoing in nature. This does not mean that the problems are continuous; there may be intermittent periods of full recovery or enduring long-term recovery, and some can fully recover.
- Diagnoses: For example, schizophrenia, mood disorders, organic brain syndrome, and paranoid and other psychoses. Other diagnosable disorders such as severe personality disorder, concurrent disorder and dual diagnosis are also included. (Making It Happen Implementation Plan for Mental Health Reform (MOHLTC 1999)

Stigma: is attached to people or groups who are viewed as different from society's norms, mainstream behaviours or identities. In effect, stigma is often used as a way of discrediting, isolating and ultimately attempting to control people who fall within a stigmatized group (Canale, 2001). It is a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation. (Weiss and Ramakrishan, 2004.)

Peer-Support: a process of providing emotional support, practical support or information exchange between people who share a common experience or identity. In the context of mental health and addictions, "peer support" includes peer counselling, peer outreach and education, or participation in peer support groups. Some peer support roles are voluntary, while others are paid positions in organizations.

Trauma-informed Services: take into account the impact of trauma and integrate this knowledge into the services being provided. A trauma informed perspective views the behaviours as a response or coping mechanism of past or current abusive/traumatic experiences. Trauma informed services do not require that the issue be disclosed; rather, it is the understanding that trauma may have an impact in an individual's life and be prepared to work in ways that will support the individual across the continuum of services. In trauma-informed services, all staff are trauma trained and understand the impact of trauma on the lives of those who are seeking help (*Bradley, Jean Tweed Centre*)

APPENDIX 2: Potential Goals and Outcomes

This table articulates some potential long-term goals and outcomes of the strategy through the lens of consumer partnership. The goals are articulated from three perspectives: that of the person with lived experience (PWLE), that of the service provider/organization, and that of the system as a whole. The proposed outcome measures are ways we may be able to gauge success, both within the health system and in other partner sectors.

Goals/Outcomes	Proposed Outcome Measures
PWLE of mental illness, problematic substance use and gambling achieve or experience: • Empowerment to manage their own health care to their individual capacity and the extent desired • Improved quality of life • Improved health outcomes • Improved social functioning and connection • Decreased stigma and discrimination • Satisfaction with mental health and addiction services and supports	• % of people in stable housing • % of people engaged in self-defined meaningful activity such as employment, volunteer work, school, training • % of people with at least one meaningful social connection or relationship • Reduced contact with the justice system • Reduced contact with emergency healthcare services • Level of service user satisfaction
Mental health and addictions organizations which: • Regard PWLE as equal partners in determining their own service or treatment needs and care • Provide services which are responsive to individual choice and capacities • Actively address stigma and discrimination	• % of mental health and addictions organizations with PWLE self-evaluation as part of treatment or care planning • % of mental health and addictions organizations with recovery and harm reduction approaches to service delivery • % of mental health and addictions organizations that utilize a "strength-based" approach which builds on a person's positive attributes and abilities
A mental health and addictions system which: • Values the contribution and expertise of PWLE and includes them in meaningful decision	• % of mental health and addictions organizations with dedicated PWLE staff and board positions • % of mental health and addictions organizations with service user advisory

making roles at every level: o planning and design o funding o research o service delivery o professional training o measurement, monitoring and evaluation • Provides sustained opportunities to enhance PWLE capacities • Ensures the sustainability of PWLE/consumer/survivor/peer initiatives, support and mutual aid as critical, evidence-based services • Addresses stigma and discrimination	committees • % of mental health and addictions organizations with PWLE-led orientation or staff training sessions • % of mental health and addictions organizations with service user satisfaction surveys/mechanisms • % of mental health and addictions organizations with PWLE-led programs as an integral aspect of service delivery • Inclusion of PWLE in criteria for mental health and addictions program funding (LHIN level) • # of mental health and addictions research funding bodies which include PWLE involvement in grant criteria • # of mental health and addictions research funding bodies with dedicated funding for Participatory Action Research • # of research projects focused on PWLE/peer/consumer programs and initiatives • # of training, capacity building and mentorship opportunities for PWLE • # of sustained opportunities for education by PWLE (e.g. speaker's bureaus, education in schools, educational materials, media campaigns) • % of organizations and businesses with policies to address systemic discrimination (e.g. hiring practices, client complaints processes, advisory committees, etc.) • # of autonomous peer-run programs and organizations

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