

**Falling Through the Cracks:
An evaluation of the need for integrated mental health services and
harm reduction services**

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Executive Summary

This report focus on the health care service experiences and needs of people with two characteristics (1) they have received, or want help with mental health issues, or issues with the mental health treatment system, and (2) they are users of illicit drugs. Services for substance use are typically provided by different agencies than services for mental health. These agencies typically demand that the consumer deal with the other issue before they receive services, e.g. consumers are told they must deal with their drug use before receiving mental health services. This situation means that many people in this population fall through the cracks of the service system and receive inadequate health care services. Moreover, stigma associated with drug use and mental health treatment can contribute to other factors that place people in this population at increased risk of serious physical problems, such as HIV/AIDS and other infectious diseases. With this in mind, we designed a study that would provide information about how best to provide services to these people. Specifically, we investigate how the integration of mental health and drug use services might help to reduce mental and physical health and social problems for people in East Toronto who are active users of illicit drugs.

Our research is also guided by an interest in integrating the philosophy of harm reduction into mental health services. The literature on services for people with concurrent mental health and illicit drug use issues indicates that one of the major limitations is that services are not integrated. In particular, there have been few attempts to provide integrated services under the umbrella of a harm reduction philosophy. It is critical to provide services in a harm reduction framework because many people with concurrent issues avoid services that are accompanied by pressures to abstain from drug use, and avoid services from providers with whom they do not feel comfortable. After reviewing the literature on services and health risks, we outline how harm reduction service models differ from other models that suggests that services integrated under a harm reduction framework will more effectively meet the needs people those with concurrent substance abuse and mental health issues.

The literature indicates that at the program level integrated services would involve provision of mental health and substance abuse treatments in a single program, in which clients receive coherent treatment rather than a contradictory set of messages from different providers. The research presented here takes us forward in that direction.

The Study

The research was conducted as a community-academic partnership and participatory action research (PAR) project. Two community agencies, Alternatives The East York Counselling Agency and COUNTERfit Harm Reduction Program partnered with two academic researchers from the Department of Sociology at the University of Toronto. We asked four groups of service users and two groups of service providers a range of questions that elicited valuable information about the types of services needed, and the types of skills required of those providing services. Twenty-seven service users and

twelve service providers participated in the focus groups.

The following issues and themes emerged from our initial analysis of data from the focus groups with services users: the need for services that ensure safety on a number of levels; the desire that staff in service agencies possess a range of lived experience, knowledge and skills, as well as an attitude of respect, and the need for flexibility in services. Service users reported that most current service systems, and in particular hospital-based services, have not met those needs. Service users were especially critical of methadone programs, although some found methadone useful in dealing with their drug problems. Respondent reports indicate that methadone use was only a small part of the many coping strategies that could be more well-supported by service providers. This includes support for safer use of illicit drugs.

In focus groups with service providers, some providers pointed out that the only coping mechanism some users have is illicit drug use. Because of this, stopping illicit drug use can decrease coping capacities. Many service providers reported that they adopted a harm reduction perspective because that perspective fit with an approach where both the strengths and weaknesses of clients are appreciated, and where strengths and resources are built upon. Many service providers believed that this approach is frequently undermined in a system that is governed by a medical model that requires "abstinence" before dealing with mental health problems. Many providers also saw a need for greater staff power in relation to medical doctors. Yet, both service providers and users also identified a need for more access to information, both formal and informal, about mental health, drugs, and other issues.

Recommendations

This report concludes by making five specific recommendations concerning what the ideal service for those with mental health and drug use issues. These recommendations are:

1. Integration of harm reduction mental health service. This will involve developing a program that does not stigmatize drug users or mental health consumer/survivors that does not force them either to forgo treatment or lie about their drug use.
2. Service components: community based; outreach; flexible hours and location of services; counselling and community support; medical supports offered from a harm reduction perspective; advocacy and education to medical service providers; safe place for drug breaks
3. Staff Qualities: non-judgmental attitudes; staff with lived experiences; skills including counselling, system navigation and trained in harm reduction philosophy.
4. Education and Information: Effects of drugs, medications, interactions, and treatment options and alternatives; Development of harm reduction based counselling on drug use.
5. Community Development: Supporting the community to develop

informal harm reduction based supports for this community; Education of ancillary services to promote working with harm reduction models.

Our research suggests some concrete ways to develop our existing partnerships in South-East Toronto. In addition to the need for dedicated staff to provide community based harm reduction support and counselling we must enhance our existing partnership relationships with community health, mental health housing and legal supports. We can attempt to acquire and use sessional funds to pay medicals staff for consultation with program staff and service users. This is similar to a shared care model currently utilized by Alternatives, which is used to create a type of "one-stop shopping". In this model psychiatric and community medical services are provided and extended beyond face-to-face and fee for service relationships to assist in providing direct education to service users and providers as well as toward providing flexible services and outreach in the community collaboratively with community support counsellors. This type of model would allow for us to meet the expressed needs of service users for client directed medical and psychiatric support when and where they are needed.

There is a clearly identified need not only for an integrated service but for community development, education and systemic advocacy. Service users and providers could collaborate to create and deliver mental health/harm reduction education materials for the service user and provider communities. Education initiatives ought to include the community health, mental health and institutional care sectors and have an anti-discrimination focus. There is a need for accessible materials that outline the real risks of medication and drug interactions and effects (similar to materials that have been developed for HIV/AIDS medications) as well as materials that explore alternatives to traditional treatment options for this community.

Our research has put us in a better position to further develop and assess a community support model that integrates harm reduction with mental health services. We believe it is necessary to design and evaluate a program in a way that is methodologically rigorous and includes the community at every stage of the study. The research presented in this report is a first step for improving the services available to and the lives of community members dealing with concurrent mental health and drug use issues. We must now acquire resources and funding to create a dedicated harm reduction/mental health program to provide service and create system changes as outlined above, and to evaluate the effectiveness of those changes.

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Statistics on people with persistent mental health problems indicate that between 30-75% also have drug use problems (Health Canada, 2001); Indeed, "substance abuse is the most common and clinically significant comorbid disorder among adults with severe mental illness" (Drake et al., 2001). Moreover, "the prevalence of comorbidity is high in the general and treatment-seeking populations in Ontario (Beitchman et al 2001; Ross 1995). Yet the unique problems of people with concurrent substance use and mental health issues has largely been ignored in the planning, implementation and evaluation of mental health and substance abuse services (Health Canada, 2001). Few services are tailored specifically for people who use drugs, intend to continue to use drugs, and who have mental health issues. Instead of receiving services, many people with concurrent issues in Toronto are "bounced" between the mental health and addiction systems. This practice stems from the policies that guide service provision in each system. Agencies in both the substance abuse and mental health service systems frequently demand that the consumer deal with the "other" issue before they receive services. In sum, "substance abuse and mental health services in the community have typically worked in isolation and often from competing perspectives" (Health Canada, 2001).

Our research attempts to address the gap in services for those experiencing concurrent mental health and drug use issues. We address two broad questions: first, what problems do people with serious mental health issues and who also use illicit drugs confront?; and second, how can services best be provided to people in East Toronto who have concurrent drug use and mental health issues? Specifically, we are interested in finding out which services will help to reduce mental and physical health and social problems for people who are active users of illicit drugs. We also believe it is important to determine how

services can be organized so that people in this population avoid developing additional problems.

Before describing our research, we outline what previous studies and direct service experience with this population have shown. We then briefly describe how the current service system in Toronto deals with clients who are actively using illicit drugs, and need mental health services or who are dealing with past negative experiences with the mental health system (i.e. who see themselves as survivors of the system). A basic limitation of the current service system for people with concurrent substance use and mental health issues (i.e. the population with "concurrent issues") is that services are not integrated. In particular, there have been few attempts to provide integrated services under the umbrella of a harm reduction philosophy (Marlatt, Blume & Parks 2001). The availability of services provided in a harm reduction framework is critical because many people with concurrent issues avoid services that are accompanied by pressures to abstain from drug use, and avoid services from providers with whom they do not feel comfortable (Ross & Cunningham 1999).

Context and Background

The lack of appropriate services for those with concurrent problems has had consequences that extend beyond the persistence or worsening of mental health issues or drug use (Carey et al, 1995; Drake et al, 2001; Drake, Mercer-McFadden, Mueser, McHugo and Bond, 1998). Drug users with serious mental health problems are at increased risk of needle sharing (Davis, 1998; Knox et al., 1994; Susser et al., 1997; Susser et al., 1996; Carey et al., 1997) and have reduced access to needle exchanges (Davis, 1998). Furthermore, people with "concurrent disorders" are at increased risk of hospitalization and physical illness, such as such as HIV/infectious diseases (Drake et al., 2001; Carey et al., 1997; Carey et al., 1995; Krakow et al., 1998). The provision of hospital based and intensive services for this population results in economic costs that could be avoided if their problems were more effectively addressed before expensive

services such as hospitalization become necessary, or more severe illnesses (e.g. HIV) develop.

Physical health risks present only the tip of the iceberg of harms to which people in this population are exposed. People with concurrent mental health and drug use problems are at increased risk for homelessness and inadequate housing, lack of employment, poverty, and violent victimization (Hiday et al. 1999; Knox et al., 1994; Susser et al., 1997; Alverson et al., 2000; Drake & Carey, 1996). A broad range of services are necessary to maintain the health of those exposed to such a broad range of risks.

Unfortunately, the range of services offered to people with "concurrent disorders" has been very limited. Most programs have been based on abstinence where the user is required to stop or "abstain" from drug use in order to receive treatment (Phillips, 1998). Recent research on abstinence-based programs indicates that these programs are rarely successful in producing abstinence (Drake et al., 2001; Carey et al., 2000; Bellack & Gearson, 1998). Others also question the basic philosophy of abstinence programs for helping drug users with mental health issues. For example, one critique of abstinence programs is that many consumers/survivors use drugs as a part of their coping strategies (Drake et al. 2001). This finding, although often ignored, has recently led to calls for the development and exploration of harm reduction-based interventions explicitly for mental health consumer/ survivors (Phillips 1998; Krakow et al., 1998) In sum, there is a growing recognition of a need for systematic study of the viability of abstinence versus non-abstinence goals (Carey et al. 2000).

It is the need to look for alternative models to abstinence-based mental health programs that drives much of our belief of the need to integrate a harm reduction approach. Before we can discuss what an integrated harm reduction and mental health program looks like, it is important to clarify what we mean by harm reduction. The words "harm reduction" are often used in the media and other forums. Yet the term is often misused and misunderstood. To clarify what we mean when we use the term harm reduction, we provide an overview of the harm reduction approach.

The Harm Reduction Approach

Like their alcohol-drinking counterparts, most illicit drug users are “social users (Brecher, 1972; Sharp et al., 1991). Moreover, most illicit drug users go through life undetected. Yet illicit drug use, as the name implies, is illegal and its users, by default, are criminals. Therefore those who use illicit drugs in a manageable way, have every reason to conceal their drug use. European studies indicate that many people are successful in this endeavor, and the great majority of illicit drug users are highly functional, and experience little or no deleterious effect on their physical or mental well-being (Sharp et al, 1991). This is surprising, given the stress, adulterants, exorbitant prices and violence to which illicit drug users are exposed. Some researchers (Sharp et al, 2003) and service providers argue that many drug users have a high level of functioning despite the negative consequences of use. They argue that illicit drugs can have beneficial effects on functioning and the health of some people. Opiates, for example, are known to enhance a person’s mood and immune system and act as anti-depressants (Privat et al., 1998 ; Burnette et al., 1999; Bodkin et al., 1995). This suggests that a person’s well being, or lack of it, should not be automatically attributed to her or his drug use.

A recognition of the strengths and abilities of illicit drug users to choose their own way of life lies at the core of a harm reduction service philosophy. Proponents of the harm reduction approach believe that the rights and humanity of drug users must be respected, and that drug users should be given the same level of access to health care, education, housing, employment, and other social goods as the rest of the community. Health care services that address the need of the drug using populations from a harm reduction perspective include confidential and easy access to the tools and information necessary to keep them healthy. Programs such as methadone therapy, needle exchanges, and harm reduction based counseling are among the core services required. Agencies providing services from a harm reduction perspective also frequently

provide education for the community at large, and advocate for changes to oppressive drug policies and laws.

We next briefly describe next how two agencies in Toronto motivated by a harm reduction philosophy operate. This provides a concrete example of how mental health services can be improved when a harm reduction approach is incorporated. Following this section, we provide a more general discussion of how mental health services, and the service system as a whole, could be improved by providing more integrated services following a harm reduction model (Zweben 2000).

Current Harm Reduction Services for People : A Case Study

Alternatives The East York Counselling Agency (Alternatives) and COUNTERfit Harm Reduction Program (COUNTERfit or CfHRP) are two programs in Toronto that provide services that are fundamentally guided by a harm reduction philosophy. These agencies provide counselling, the dissemination of harm reduction materials, community support programs, education and advocacy. Both agencies provide services to people in East Toronto who experience serious mental health problems and who are illicit drug users. CfHRP is an initiative of the South Riverdale Community Health Centre. The following example describes how these agencies currently operate.

In 1999 a service user who had been accessing COUNTERfit for some time disclosed that he was feeling quite depressed and that he needed help in this regard. This man had been using amphetamines intravenously for over fifteen years and was certain that his drug use had little nothing to do with his depression. He said he wanted help for his mental and emotional health, rather than his drug use. Indeed, he was adamant that he did NOT want to hear anyone pontificate about his drug use.

An outreach worker at CfHRP spoke with the Community Health Center's psychiatrist and relayed this service user's concerns to her; reiterating that this person was seeking psychiatric help for his depression and not his drug use. The Outreach Worker reported to the psychiatrist that this service user had been

using amphetamines for a long time but had managed to maintain a relatively stable lifestyle. He had tried to seek help for depression before, but was unsuccessful because the counselors he had contacted insisted on dealing with his drug use issue rather than his mental health issue. The psychiatrist seemed amenable to dealing with this man on his own terms, so after talking to her the Outreach Worker booked an appointment. The COUNTERfit Outreach Worker pledged to his service user that the psychiatrist would address his mental health problem, and that nearly nothing, if anything, would be discussed about drugs.

By the time of the appointment, the condition of the service user had deteriorated considerably. The Outreach Worker noticed that the service user was sleeping all day, and had little motivation. Accordingly, on the day of the appointment, he dispatched a taxi to the service user's home to make sure that he made it to the appointment. Once the service user was at the Centre, the Outreach Worker reassured him that the psychiatrist would not address his drug use. After introducing the service user to the psychiatrist, he returned to his office.

Hardly five minutes had passed when the service user walked into the Harm Reduction Program's office with a piece of paper in his hand. The Outreach Worker was quite miffed to find out that, after a few minutes of discussion, the psychiatrist had simply written the name and the coordinates of a traditional drug counselor at Salvation Army Harbour Light Centre and advised the service user to visit him and address his amphetamine use. She had, subsequently, called and made an appointment for him. The service user had politely accepted the referral with no intention to follow up.

Upset with this development, the Outreach Worker called the psychiatrist for an explanation. The psychiatrist replied that she/he was convinced that a diagnosis could be attained only when the service user stopped using illicit drugs. Despite the previous communication, there had been no attempt to find out whether this service user's drug consumption was to such an extent that it had an effect on his lifestyle; or that his drug use was preventing him from functioning

“normally” in society. “You may not want to hear this”, the psychiatrist told the Outreach Worker, “there are studies out there linking prolonged amphetamine use with depression.” From the Outreach Worker’s point of view, the psychiatrist had just referred someone who was the equivalent of a social drinker to an alcohol rehabilitation centre when this person had been suffering from a completely different disorder. The CfHRP Outreach Worker then turned to Alternatives for help.

A Community Support Counsellor (CSC) from Alternatives made contact with the client. The client expressed difficulties with getting out of the apartment for appointments. The CSC began with home visits. The client made great attempts to impress upon the CSC that his drug use was not an issue that needed addressing and at first insisted that he was not using illicit drugs at all. The CSC made it clear that he would not be judgmental of drug use per se. Over time the client became trustful of the CSC’s harm reduction perspective. It eventually became apparent to the client and the CSC was that the client’s living environment was causing a significant amount of distress and anxiety, which was contributing to depression. The client was sharing his apartment with an individual who was engaged in selling drugs - the apartment was frequently busy with customers at all hours of day and night. The client felt very committed to supporting his friends and community but it was at some cost to him. Together the client and the CSC strategized ways to create a more peaceful and controlled environment while simultaneously finding other avenues to support the needs of the clients’ friends in the drug using community. For example, the CSC and COUNTERfit coordinator helped the client to participate in a community advisory committee. This intervention had the dual impact of increasing community connection of the client, while helping to reduce his depression. As the client and the CSC were working the harm reduction coordinator remained involved providing service and sharing in supporting the client.

This example illustrates the need for a greater emphasis on the integration of harm reduction into the broad spectrum of services required for this population. The willingness of mental health workers at Alternatives to use a

harm reduction perspective has resulted in a number of COUNTERfit clients accessing their service. Clients obtained community mental health support that was non-judgmental, non-medical and did not insist on compliance for the first time. As a result, there has been an increase in demand from the user community for community based mental health services from Alternatives. However, much more could be done.

This case study is also at the heart of our research. We developed this project based on unmet needs in the community – needs that focus on mental health services from a harm reduction perspective. In the next section we discuss why it is useful to integrate mental health services with a harm reduction perspective.

Integrating Services from a Harm Reduction Perspective

Currently, there are too few spaces in programs guided by a harm reduction philosophy to provide mental health services to all the people with concurrent issues who want them. Similarly, few mental health programs are addressing problematic drug use in an effective manner (Drake et al., 2001; Davis, 1998).

In Toronto there is wide recognition that lack of service integration is a fundamental shortcoming. For example, Toronto-Peel Mental Health Implementation Task Force Phase 2 consultation document stated “The system must be responsive to the needs of all people who are living with a serious mental illness. Particular emphasis must be placed on increasing the system’s capacity to meet the needs of people who historically been under-served and whose needs have been under met (e.g., people living with serious mental illness who are...living with a substance use problem” (2002, pg. 31).

Although there is a growing recognition of the need for integrated services, and the need for services provided from a harm reduction perspective is especially great, there are many barriers to service provision. One barrier is that most service agencies take an abstinence approach and have adopted policies that conflict with a harm reduction approach. There are also many technical and logistical barriers to the effective construction of services that integrate harm reduction services with other services. For example, Drake et al. notes that “no

consensus exists on specific approaches to individual counselling, group treatment, family intervention, housing, medication, and other components” of services (2001). Service providers within different service systems often recognize that they do not have the skills and knowledge to provide services to clients with concurrent mental health and drug use issues (Health Canada Best practices 2001; Carey et al., 2000).

Other barriers to services are specific to Toronto. Beyond the collaboration between Alternatives and COUNTERfit there are few agencies or service providers in Toronto who offer concurrent community mental health and harm reduction support in one integrated program. This is in contrast to programs that support consumers/survivors in safer sex risk reduction initiatives (Weinhardt et al., 1997; Kelly et al., 1997; Kalichman et al., 1995). Although advances have been made over the past two decades in terms of integrating people with severe mental illnesses into the community, over the past two decade” (Health Canada, 2001 pg.viii), there is still a roadblock to mental health services for those who use drugs. The trend toward a broad psychosocial rehabilitation perspective, including advocacy for supporting the person in a wide variety of areas, including housing, employment, recreation and social networks, has not been extensively applied when clients have drug use issues. Specifically, services that are consumer-run and “...which bring an experiential perspective to service delivery and support” (Health Canada, 2001pg.17) have not been developed. The lack of services for illicit drug users who have mental health problems coincides with and contributes to limited access to existing services by people with serious mental health issues who either cannot or choose not to abstain from drug use.

Although the need for services for the population with concurrent disorders is clear, there are many questions about the types of services that would be most beneficial, and how services should be structured. We know that in general, at the program level integrated services would involve “mental health treatments and substance abuse treatments that are brought together by the same clinicians/support workers, or team of clinicians/support workers, in the same program (Health Canada, 2001). Integrated programs “...ensure that the

individual receives a consistent explanation of illness/problems and a coherent prescription for treatment rather than a contradictory set of messages from different providers.” (Health Canada, 2001 pg. 15). But many programmatic specifics must be worked out, and the research presented here takes us forward in that direction.

At the systemic level, integration involves “...the development of enduring linkages between service providers or treatment units within a system, or across multiple systems, to facilitate the provision of service to individuals at the local level. Mental health treatment and substance abuse treatment can, therefore, be brought together by two or more clinicians/support workers working for different treatment units or service providers. Various coordination and collaborative arrangements are used to develop and implement an integrated treatment plan” (Health Canada, 2001 pg. vii of executive summary). The Toronto-Peel Mental Health Implementation Task Force Phase 2 consultation document includes a recommendation for the construction of “coordinated, not centralized ‘single point’ system of access [which is] responsive to all people” (2002). Clearly there is a great need for a re-structuring of the service system. Yet previous studies have not asked service users or providers what an ideal system might look like.

Evidence has been accumulating that integrated treatment programs that include outreach, flexibility, relationship building, psychosocial rehabilitation and harm reduction measures are particularly successful in helping clients to maintain their health (Carey et al., 2000; Drake et al, 2001; Philips, 1998; Health Canada, 2001; Zweben 2000). Flexibility is critical because clients have diverse needs.

The Use of This Research

It is important to consult with service users, and those who currently provide services for them, when embarking on the construction of new services. The research presented here involved consultations with both groups in the framework of focus groups. We asked four groups of service users and two groups of service providers a range of questions that elicited valuable information about the types of services needed, and the types of skills required of those

providing services. The details about those consultations are presented below, as are some of our initial results. We expect to continue to analyze these data, and we anticipate that the information obtained will help us to refine the recommendation presented at that end of this document. We also expect that the innovations suggested by this research will be critically evaluated once they are put in place. Thus, we envision the research presented in this report as one step in a continuing process of research guided program and system change.

Methods

This research was designed as a community-academic partnership and participatory action research (PAR) project. Our conceptualization of a PAR project involves the active participation of community members who participate in all levels of the research, including the direction of the research. Two community agencies, Alternatives and COUNTERfit partnered with two academic researchers from the Department of Sociology at the University of Toronto (see the accompanying Process Report for more information on the community-academic partnership).

Four focus groups of service users were held in August 2002 in Toronto, Ontario. Flyers advertising the focus groups were faxed and hand-delivered to a variety of community agencies and other organizations that have clients with drug and/or mental health issues. Participants interested in attending one of the focus groups phoned the researchers listed. If a community worker phoned on behalf of a service user, we requested that the service user call us directly. We screened participants to ensure they were dealing with concurrent mental health and drug issues. Participants were also informed that they would receive \$40 for compensation of their time if they completed the focus groups.

Twenty-seven service users participated in the four focus groups. Eleven were male and 16 were female. Participants ranged in age from thirty to fifty-two years old. Approximately half of the participants were white, four were Native, four were Black, and the remaining 5 were either other race/ethnicity or unknown. In terms of housing, thirteen of the participants rented an apartment, though

many listed this was a shared apartment. Eight participants lived in shelters, two in boarding houses, one in a house-sitting situation, one on the street and one in a group home. Participants listed a number of mental health issues they were dealing with, including (in order of frequency mentioned) depression; sleep disorders, anxiety and other issues (such as child abuse, mania, anger/violence, schizophrenia, and compulsive-obsessive disorder). The length of time participants stated they had been dealing with their mental health issues ranged from 2 years to "my whole life" or "forever", including some that mentioned 30 to 40 years of problems. Participants also mentioned they used a range of drugs, with most mentioning at least two drugs. In order of frequency, these drugs are cocaine/crack, heroin, marijuana/pot, morphine, Valium, alcohol, Percocet or Percodan (Percs), hash, and speed. Other drugs used by only one person include ecstasy, Tylenol 3, and Paxil. We note that none of the participants were less than 30 years old. We do not believe this means that young adults are not experiencing these problems. Since we solicited participants through existing service agencies, it may be that young adults are not connected nor have access to service agencies in the same way as those over 30 do.

Two focus groups of service providers were held in September 2002 in Toronto, Ontario. Participants in these focus groups were solicited similarly to those of service users. Flyers were faxed and delivered to agencies and those interested were asked to phone one of the researchers. The two community partners, Jason Altenberg and Raffi Balian also made specific requests to some agencies. We attempted to get a cross-section of service providers for each group to include those doing direct community outreach and working in hospital or clinic setting. Twelve service providers participated in the two focus groups. Two of the service providers were male and ten were female. They ranged in age from 31 to 64 years old. Nine of the eleven participants worked in community-based services such as shelters and community health centres. Only two worked in hospital-based or affiliated services. There was some variability in the positions worked within their organizations, with three working as direct outreach support workers, four as caseworkers, four working as counsellors, and

one as a program manager. Three of the participants stated they were current or former drug users and mental health survivors, six stated they were not and three did not answer the question. Participants had worked as service providers for almost two years to eighteen years. Training of service providers included relevant B.A. and M.A. degrees, including social work and psychology, ongoing training in mental health issues, on-the-job training and life experience.

Each focus group was co-facilitated by two moderators, one academic researcher and one community researcher. As part of our commitment to an equal community-academic partnership, we believe this was the best way to solicit information from the focus group participants as community researchers and academic researchers bring to the project expertise in different issues. Sandy Welsh, representing the academic researchers, was a co-facilitator for all the focus groups. Jason Altenberg co-facilitated two service user and one service provider focus group as did Raffi Balian. Focus groups were audio recorded for transcription. Also in attendance was a research assistant who took notes on the order of speakers in order to improve the accuracy of the transcription.

The transcripts of each focus group were coded independently by the four investigators and a graduate student research assistant using a constant comparative analysis (Berg, 1989). The central issues that emerged in each group were identified through the key concepts or phrases used by participants during the discussion. After transcriptions were available, the four investigators met to compare and combine their independent analyses. This kind of simultaneous data collection and analysis made it possible to explore and expand on themes from earlier focus groups at subsequent sessions. During the next phase of the analysis the investigators identified similarities, contrasts and potential connections among the concepts within and amongst each focus group. The final step in the analysis involved the development of the major themes and the identification of phrases or quotations that most accurately illustrated these themes. The software program QSR NVivo (2001) was used to organize and code the data on the relevant themes.

Research Results

The results from our research are organized by the major themes emerging from the focus groups. Focus group participants provide important insight into the positive and negative experiences with services, why harm reduction approach is useful, and their vision for the ideal service for those with concurrent mental health and drug use issues.

Experiences with Services

Service users expressed both positive and negative feelings about their experiences with drug and mental health programs. Generally, they felt good about services that provided a safe place away from drugs, and when they felt that service providers and medical professionals were willing to listen and treat them like individuals. Negative comments focused on difficulties accessing services, problems with Methadone Maintenance Therapy (MMT) and treatment in hospitals. One of the main issues that service users had with hospitals, as well as with doctors and service providers, was that they felt stigmatized. Upon disclosing their drug or mental health issues, service users felt that they were stereotyped as liars or addicts, and they were often accused of “drug seeking behaviour”. In many cases, they felt that this affected the level of care they received.

Throughout all of their discussions, the issue of Stigma emerged as problematic for many service users. Yet despite the prevalence of stigmatization, service users did have positive experiences with some services, such as those that provided a safe place away from drugs.

A Safe Place: Service users had positive comments about service facilities that provided a safe place to stay, a space where they could get away from, or take a break from drugs.

Well when I was with uh really heavy in the drug problems, I just wanted to be locked up, but there, there didn't seem to, I couldn't get myself locked up, right? You know. [laughter] That was what I wanted at that time, you know, but it, you know, maybe that's not the best way to do things, I don't know, but that's what I felt I needed and I wanted, I mean to, to be closed off from where all the outside influences sort of thing. I guess that's why I and that looked into the Donwood, cause I know you can, they do have inpatients, right?

Another service user shared his/her experience with a mental health facility that provided a place to escape from drugs for a few days.

...I was having quite a hard time living where I was living and I was getting overwhelmed by the drug scene and I was taking too many drugs and that sort of stuff and I was going a little bit out of my mind and I called up the Gerstein centre and I asked them for help and poof, right away, I couldn't believe it, they put me in the same day and they took me and they let me stay for three days, just to get my head focused right, to make the proper calls, to stay off the drugs and that, and to get out of the scene I was in, they let me stay there three days, I had a chance to talk it out with people, there was other people there staying there as well. And I, I really recommend the Gerstein to anybody, I mean, if you need a break, you need to get away from it, even though you have the access to go outside, that's your, that's called your ability, your gonna get back involved in drugs, whatever the case might be, or into a bad scene, that's up to you, but I found that the Gerstein Centre was a great help for me.

One service user described a good experience she had at an alcohol treatment facility. Feeling safe was an important part of why she felt so positive about her experience.

Ok, I had a positive experience when I first tried to, well, recognize that I needed help with alcohol and I went to a women's own detox [detoxification centre] and it was just awesome, like it was amazing there, the staff there, most of them, were addicts themselves, like the majority, and that was in 1994 and I don't know, well they helped me, they let me stay there, it was very safe, you know to be there, I felt really safe and I stayed there for like a month, before I went into treatment and stuff and I and I went to the Donwood and I stayed clean for five years, I don't know, like I mean, I'm not having any luck now, but when I was first, like for somebody to maybe, makes their first attempt to deal with the problem like it, it was, it was fairly cool and I'm getting there, it was very helpful.

In addition to feeling safe, this woman had a good experience with the staff at her treatment facility. This leads to the next theme that emerged when discussing services. Service users had strong feelings about staff – both in terms of staff's role in contributing to positive experiences as well as negative experiences with services.

Staff: Staff had a big impact on services users' experiences, positive as well as negative. Some of the service users felt that staff were unavailable or inattentive to their needs.

...sometimes I don't see him for weeks, you know, he just sort of leaves me floating and that's it.

One of the most common complaints that service users had about staff was that they did not understand and could not relate to their clients. One service user felt that service providers' class status and lack of personal lived experience with drug use and mental health issues hampered their ability to understand his situation.

Well, I just find that like you know a lot of these, like, a lot of people at [service provider name removed] don't understand the situation you're in, because they've never been in it. They're middle class people who've gone to university, gotten a degree and have never had to live on a maximum of nine hundred and thirty dollars a month and have never, you know, experienced any mental health problems of their own or any addiction problems

This inability of staff to understand their clients' predicaments made some service users feel dehumanized. One person reported feeling that she was being treated more like an animal, or just a number, than a person.

...they weren't being thoughtful towards my mentality or my feelings. They were, you know, they were treating me as like you know like, like a, in the, in the science lab, right, like guinea pigs in a cage...let's see what's wrong with this guy today, you know. It was that type of thing, it was like, I felt like I was just a, like a number, you know what I mean? Like a figure, I wasn't being treated as a person.

Another service user described some of the service providers she dealt with as abusive and lacking compassion.

...people with absolutely no humanitarian side to them, no one has, they've got no street smarts, they have no life skills, they're part of their little you know, organization thing, and it goes from one place to the next, ...and that's where all the negativity starts, because the staff are very abusive to the people that are in there, so that's what's turning people right out that door again, so that's why people just say, screw it, I'm out on the street.

Negative experiences were not universal amongst the service users in our focus groups. Some found their service providers attentive and helpful, and did feel that they were treated as an individual.

I find community service to be a little bit more beneficial, because they want to deal with you as an individual and you don't get caught up in the bureaucracy. I've always found that the people, well it depends, it depends [on] you and the individual you're dealing with, but I've always found that the people from community support point of view have been always willing to, attentive to listen, and also willing to help you find the services [you] need.

Willingness to listen was often mentioned as an important staff quality. It was also important that service users felt believed and not judged by staff.

I've got anxiety and depression and the place I was staying was making me incredibly anxious and Sistering really helped me too. I mean they come right out to meet you, that was great, you didn't have to go anywhere or you know, they weren't judgmental at all, their first instinct was to believe you, no matter how outrageous it sounded.

Well, I'd like to say that my experience with Alternatives is that I didn't feel like coming out [to where they were located], or I didn't you know, like I was unsure. They came to me, in my home and I didn't feel that anything that I said like that I was being judged like or anything and, and I felt like for me, that's what I needed. If I wanted to talk I could talk, if I didn't fine. You know, I wasn't pressured and I didn't feel that the person was looking down on me, which really helps

In general, service users had positive experiences when they felt that service providers were treating them with a bit of respect. They want to be treated as individuals, by staff persons who understand their issues and listen without passing judgment. It is also important to note that both of these service users are referring to outreach services that come to where the service users are. Implicit in their comments is that part of respect for service users involves delivering services where service users live and spend time.

Access to Services: Access to services were an issue for some service users. In general, access seemed to be less of an issue for them than things such as staff. Most commonly mentioned as obstacles to service access were waiting periods and hours of operation.

Like, you know, only one day at one hour that you're allowed to go in for orientation and get you know admitted, so that, that I found very restrictive. And so then I never really got any professional help for the addiction, because of that. I guess if I really wanted to I could've made it, but like I say, you know...

I would agree with her, I tried to go through the Donwood last year. I found that the staff there was knowledgeable about my problems and in some respects they were very helpful, but much as like she had mentioned, when I needed the help, I found that it was just too restrictive. You had to wait, like the intake is like a month, a month and a half sometimes and then when you go to the orientation session, it could be another couple weeks and so, essentially it just kind of like leaving you somewhat naked to deal with your problems on your own.

Another service user highlighted the need for flexible hours. She had a well meaning doctor who told her to call whenever she needed to.

...but my problems don't happen between nine and five, so I always thought that was the most ludicrous thing he could ever say to me. You know, because I couldn't get a hold of him at ten o'clock at night, you know, so.

Service users also identified 'services that come to you' as really useful in gaining access to services. One service user pointed out that many of the

people who require help have mental health issues that prevent them from leaving the house or being able to keep appointments.

...and if you have anxieties, someone who can go places with you, cause I know, when I, at my worst I couldn't fucking walk through that door and you, that's why Sistering's good, that's the one thing they do, they come and get you. And a lot of people just need that, they'll go, they'll do stuff, everyone complains, well nobody shows up to appointments, it's because they're all fucked up, fucking get them, you know.

Experiences with Hospitals: None of the service users discussed positive hospital experiences. In general, two main themes surrounding hospital services emerged: service users did not find the treatment they received in hospital to be helpful, and they felt that hospitals stigmatized them because of their drug use or mental health. As the following quotes show, stigma was a big issue for service users, both in their service experiences and in life.

...the thing that constantly gets me down is that people judge me to be a liar. And they don't believe anything I have to say, so why should I bother?

...There is a stigmatization that comes with having an affliction or an addiction problem. [The] perception of how people look upon you and then they think you're weak or damaged or diseased and they don't want to be with you, yeah sure, it's, friends of mine, you know, they often say, well, how can you do so well on one level and your life is a mess in, in other ways. And I've seen that approach from friends and services...

Service users often felt that this stigma surrounding illicit drug use greatly impacted the care they received in hospitals, as one service user articulated.

...I find this every time I go to emergency, I don't tell them I'm on this medication, I refuse to, now, because you get treated like crap, all of a sudden, you're a druggo, off of some gutter alley way somewhere and god forbid if they ever get around to seeing you or whatever.

One service provider who also self-identifies as an HIV positive drug user, told us that her experiences with hospitals usually involved her being stigmatized for her drug use.

I found that most prevalent in the mental health system and the hospital systems particularly. You know, when I go for something related to my HIV, the very first question they ask, beside my viral load and my cd4 count, is do I use drugs. And my answer is it's none of your business, it doesn't affect my HIV. I'm here, because I have a cough...and then I always find pamphlets, twelve step pamphlets, you know, with my chart. [laughter] More [paper] to waste, you know, I mean, twelve step programs work with some people, it's not my philosophy.

In this account, rather than just providing the requested medical service, the hospital repeatedly attempts to impose a drug abstinence program on this individual.

Another service user, who was also on methadone, experienced difficulty around the birth of her son and her wish to breastfeed her son. She had gained approval, through her midwife, to breastfeed, but all was turned upside down when a medical doctor at the hospital got involved and the service user refused to take (another) HIV/AIDS test:

...because she [the service user speaking in third person] doesn't have an AIDS test, you're not going to let her breastfeed [the doctor says], that wasn't, that wasn't supposed to come up. It was a real power from all they're trips that they pulled on me. And the doctor said, well, you're a drug user, did you use needles. I said yes, but I never, ever shared needles. Well, you're a drug addict, drug addicts lie. Says this right into my face, right in front of the midwife and I just kept my mouth shut, there's nothing you can say against a stereotype, but because I was being stereotyped and treated horrendously, we went ahead and did the breastfeeding anyway. Children's Aid of course are involved always when there's a methadone situation and that wasn't a big problem, except the CAS worker said that because I refused to be checked for HIV, could they check [son's name], they wanted to check my son. I, and at that point, I'd already agreed with my midwife that she would be checking,... so I said to my midwife, just go ahead and run the test, I don't really care, but I'm not going to go to the doctor, I'll do it through her, so she had run the test, so after they discovered that I had uh gone ahead and drawn blood for the test, they, they started treating me a lot better and said ok then.... Anyway, it's about how I was treated under the circumstances. So, I was told I was a liar and uh they were very satisfied that they did the test...

The stigma surrounding drug use led to a terrible hospital experience for this young mother, where she felt judged by medical professionals, as well as a loss of control over her situation.

Service users also felt stigmatized due to their mental health issues. One service user described the difficulties she experienced getting treatment at a hospital for a head injury. Upon hearing that she is staying at a shelter for women with mental health problems, she was promptly moved to the psychiatric ward.

Because the doctor had seen Evangeline Women's Shelter, immediately, I was taken to the psychiatric ward. One thirty in the morning I'm in an easy boy chair, I have fallen asleep, doctor comes on, pushes me, to wake me up. He says, so what're you doing here? And, oh, it's like, I don't, you know, I'm trying to wake. I said, I guess they put me over because it was full. No, he goes, so [service users name], he says, you gonna kill somebody? [laughs] Like this, I said, no. He goes, are you going to kill yourself? I says, no. [laughs] Like not yet. But I meant it as a joke. Like, you know, or whatever. He goes, well then, I don't see why you're here, you can go... I was never treated, never treated. Just automatically took to the psych ward and then asked if I [would] kill anybody, kill myself, that was it. Meanwhile three o'clock in the morning, some guy goes insane, the police are all there, like all of this and nobody looked at the cut on my head. Nobody gave me an x-ray or anything else to find out if I was [o.k.], how severe my seizure was or nothing, right? That was the ultimate...

When service users entered hospitals for mental health treatment, they did not find this treatment to be useful. In general, they found that hospitals were good at keeping them fed and medicated, but were unable to really help them deal with their mental health issues. One service user expressed that what she really needed was for someone to talk to her, and to listen.

I'd rather avoid going to the hospital, because, when you go to the hospital, you don't really get the help you need. All you get is a bed, you get your food, and they pump you up with whatever. That's not helping me, I need people to listen. Anybody can put a needle in my arm and or a shot in my ass or restraining to the structure, you know... 999 Queen Street. The nut house mental institution. They locked me up in there, because I jumped in the subway track, whatever, I did a lot of things, but they locked, but when they lock you up in there it's not like they're, they're,

they lock you up, you're in one room like this, they let you run around, they shoot you up in the ass with something, I don't know what you want to call it, something that calms you down. They don't talk to you, they don't ask you what's your problem, they just stick you in this one place, you're there until they decide you're going to leave. What kind of treat, what kind of hospital is this? It's not a hospital, I don't call that treatment. I call that just a place they want to lock someone. You're loony, so they're going to lock you up behind the bar there, put some rubber walls up there and say, here, go ahead and when you stop pounding your head against the wall and you don't bleed anymore, then you're o.k., you can go. That's not what I call mental help [or] caring.

It seems that service users were, overall, much more satisfied with the community-based help they received than with hospital treatment.

Experiences with Medical Doctors: Service users had both negative and positive comments about their dealings with medical doctors. The main complaint that service users had about doctors was their unwillingness to do anything for them but prescribe medications. One methadone user described how his/her doctor would not treat any of her health conditions, and how it made her/him feel like she/he was on a methadone 'assembly line'.

Most methadone doctors they will not prescribe things to you for other problems that you might have, physical problems, all they care about is filling your prescription for methadone...it's like you're on an assembly line.

Another service user found that psychiatrists were unwilling to listen, and focused on prescribing drugs, which she did not find to be useful.

But I find that with psychiatrists and with any mental health place they don't really want to listen. Their answer is, oh, well here's a prescription, take this. So, that's not helping you because they are just putting you from one drug to a bloody nother and they're not making you independent, because they don't want to listen. As soon as you start to get into an issue, you know, what's wrong with you today, or what, blah, blah, blah. Oh I'll try this, this doesn't work, so try this and that's, sure you feel good, for a while, but it doesn't help anything

As with hospitals, service users also felt that they were being stigmatized by medical doctors. One service provider described the experience that one of her clients had with his psychiatrist. The doctor would not treat her client's mental health problems unless the client submitted to regular drug tests.

We had a client in the house that had gone through one of the [name removed] Programs. And so he was seeing the psychiatrist on an outgoing basis from [name removed] and a part of seeing the psychiatrist was getting a urine test done, even though he was no longer involved with their programs. He was one of our housing clients. We tried to get him referred to some other psychiatrist and couldn't, because he was a former drug user. But in, in order for him to get his medication, he had to do this urine test, which he didn't like doing. He was a very quiet, retiring kind of guy, so what he would just often do is not see his psychiatrist and just not get the medication. But you know and the psychiatrist was not willing, like that's part, that was part of his set up and the way that he, his practice was designed. That wasn't negotiable. So, I think that was pretty stigmatizing, I wouldn't want to go and see a doctor that I had to do a urine test every time.

The stigma of continual urine testing led this service user to avoid following through with his mental health treatments. According to one service provider, who also identifies as a service user, being denied mental health treatment because of drug use is a common occurrence. She recounted her own experience, where her psychiatrist refused to see her any more because of her illicit drug use.

I went to see her and she told me she wouldn't participate in my suicide any longer, because I was using drugs and [she] stopped seeing me. And so that's the experience I hear over and over again, with the mental health system and drug use. And the lady talking just [now] triggered that, that you know when we would go to hospital if somebody did overdose, the automatic assumption would be that the only [reason] they're here is because they've used, they've ingested too many drugs, you know, there couldn't be, possibly be any problems and then you'd be back out on the street.

Other service users though, were able to find doctors that they were quite happy with. One service user liked her psychiatrist because he did not want to see her medicated.

...and I love my psychiatrist, he rocks. He's cool, he doesn't want to see me on medication and everything like that and I trust him...

Some service users liked their doctors for many of the same reasons that they liked other service providers. Their doctors listened to them, and were able to understand their situations. One service user described his methadone doctor:

...you know, he's pretty understanding, pretty sympathetic, you know. So, it's good to have somebody that's willing to listen and, you know, know where you're coming from, kind of thing. I don't know if he's been there, but he's certainly dealt with it...

Another service user felt positively about her doctor because she believed she was listened to.

...Dr. [name removed], he'll sit there and listen to me and if I get angry he'll let me get angry, because I'm, I'm angry and I want to just lash out but I, I don't, so that he hears me. It's like, he's paying attention and like, it's not like I'm being ignored, he's there and he's listening and he's letting me, letting me let my anger out so, or my tears out, so I can release that tension that, I don't want to have to hurt myself.

Methadone Maintenance Treatment Programs: For the most part, the service users had negative comments about methadone programs. As the following conversation shows, they believed that methadone was physically damaging, and controlled too much of their lives.

...and it's [methadone] liquid cuffs. They're selling handcuffs. Each and every day of their life, they have to go out and get this bloody methadone and at the most they can get it one week at a time. What's the point? You have more freedom when you're a drug addict, because at least you can choose the time to start...

...And it's demolishing your body, every part of it, every major organ. I agree with you there, it has a very heavy effect on your body, it affects you very seriously...

...Ya, but I mean as an alternative, right, like if you're strung out you need to be on methadone for a while, ya, as a short term thing and get off fast and you know, but you need other stuff to help, but these clinics are geared to get you in there and once you're there, that's it, you're shackled.

They do not want to see you leave, they'll pump your dose up and you know it's just fucked.

Many of the service users were extremely critical of methadone treatment programs. They believed that with the frequent required trips to the methadone clinic and drug tests, the clinic had too much power over their lives.

...the whole idea of methadone and the carries [being able to carry methadone dose home with you] and if you have dirty urine, then you know you're not to have that [carries] just pisses me off. It's completely negative.

...It's [carries] not really a incentive to stay clean, it's just another way to feel resentment towards the clinic that's controlling your life far too much to begin with, you know.

They also experienced negative side effects from the methadone that they did not know about before starting the program, as the following service user explains.

...methadone's incredibly bad for you, sent me right into menopause, that was great, no one told me a thing about that, so that was fantastic, so it ruined my health and boy it depressed the hell out of me. But trying to get you know meds to help you and they stick you on Valium, well that's freaking dirty and if you've got hep C you shouldn't be on anything, cause it's just gonna waste you even faster.. So, I don't think many doctors, I just don't think the information's getting out what, what we need to help us with our problems, I mean there's just nobodies talking to each other

Despite the many negative comments about methadone treatment programs, some of the service users did find it useful in dealing with their drug problems. Even though methadone maintenance treatment is not without its problems, it would be a mistake to conclude that methadone is a problem and simply constitutes substituting one addiction for another. In fact even with all its problems, when reflecting on the role of methadone treatment programs in their lives, service users did comment on the positive effects of these programs. The main benefit was it helped people stay away from heroin use.

...myself, I'm on the methadone program myself and I find that it works, the program does work. I haven't touched any heroin in the eight months I've been on the methadone.

...this methadone every day [is a problem]. [voice: yeah] But I find, you, now that I'm off it, I wish I didn't get off, because I stayed straight.

Overall, some common themes emerge from the service users' descriptions of their service experiences. Service users felt positively about services that provided a safe, drug free place to go to, and with services that were made more accessible by having staff go to the client. They were also satisfied when they felt that service providers and doctors understood them, treated them as individuals, and were willing to listen without judging – where they didn't feel stigmatized by their drug use or mental health problems.

Stigma was a widespread issue that led to many negative experiences for service users with hospitals and medical doctors, which points to one of the reasons for the need for a harm reduction approach to concurrent issues of drug use and mental health problems. Hiding ones drug use or avoiding mental health professionals because of treatment requirements (urine testing) gets in the way of service users dealing with the issues they face. Developing a program that does not stigmatize drug users, that does not force them either to forgo treatment or lie about their drug use, is a needed step for treatment of this population. The following comment by a service user underscores the importance of the need for treatment without stigma:

I think society thinks that once you're addicted to, to an illicit drug, you're useless, that you have nothing to offer and basically I think the reason is that, has to do with the legal status as opposed to the drug itself. And um I think that, that uh, if a person was, was a hard drug user, you could stabilize the person's addiction, in, in other words, get them to a point where they're not like, you know, that they, they understand how much it takes for them to, to be, to have enough, if you know what I mean. Right? As opposed to, to find them dead in a ditch with a, with a needle stuck in their arm.

Why Harm Reduction? Balancing the “Good” and the “Bad”

The use of illicit drugs by those with mental health issues is complicated. The picture that emerges from the focus groups is that service users see both benefits and limitations to their illicit drug use. The primary benefit comes in the form of helping users cope with mental health problems, abuse, or past experiences.

Service providers were aware of, and at times were understanding of, the way their clients used illicit drugs to cope with things in their lives.

... think sometimes they're using to help alleviate symptoms, right. Like voices in their head. It's the only way that they know how to cope, but it's really making it difficult to get housing for example or get stable in other ways, so it's you know, they're doing it as a coping, and a good coping for what they're dealing with...

...you know, sometimes the mental health issues came first and their self-medicating, to get rid of the voices. In other cases, you might have, excessive use might be triggering seizures, but there's, how, why did people get to this stage? You don't suddenly use, because hey this is a good idea, let's see how much I can ingest. You know what I mean? It sounds silly. But there's, because we don't have a history, we don't know where the person is coming from, we don't know and don't need [to know], but you know, all we need, in our case, all we need to know is how we can help them at this moment, but that's such a difficult thing to, to answer isn't it?

...Well, I know I have a client who smokes up every once in a while, like, smokes some pot. It works faster than her anti-anxiety drug. And she won't do it too often, because she gets afraid that she's getting herself addicted. Or that she lives in an apartment building, she's also concerned about neighbours maybe smelling it. So, she goes through periods of on and off use of it. It's not bad, though, because it actually, I mean she's right, it works a lot faster than what her PRN does, you know. But even the whole routine of doing it, you know, it's, rolling the doob, is soothing to her, so it's not a bad thing at all. I don't know if that quite fits into harm reduction...it's that social use thing. Whereas if she has a drink, the drink doesn't work well for her and with the meds that she's taking, the drink is not a great idea. As far as I've been able to figure out, smoking pot doesn't really interfere with anything that she's taking.

...they [mental health service provider community] were talking about this new board that they're going to have or regional board that they're pushing for and again, it's only got to do with mental health. Addictions are getting swept under the table. Nobody's, you know, because they talk about mental health and addiction, because often times, and I'm working with people with mental health, they're hearing voices. Well, they're going to self-medicate, they're going to take something, because those voices are in their head constantly, telling them horrible things. So, how else are they going to shut them up? You know, you see people with things on their head. They can't stand it, they're receiving messages, so they put some, you know, tin foil, so messages will be clearer...and then they're taking drugs. So we don't know what's happening. They're getting their medication, they're getting their prescription medication, they're taking drugs, you know. We, we need a lot more crash courses, what to do and how to, you know, and you said they're going to, you're seeing a lot more? Well we'll see even more. Look at all the community, the access, the care groups that are closing or that, their shifting their, they have mandates and not quite, you know, serving up, living up to them, cause so many of the hospitals have closed that could support people.

The following discussion shows how the side effects of mental health medications contributed to clients' drug use.

Participant A: I have a past client who had some kind of psychosis, it's obvious you know that he does and that it's real, um, but he does drugs, he'll, he'll come off his medication, because of the side effects of the medication and then he'll do drugs with, which definitely exacerbates his symptoms, but you know, I have to provide him with something else to substitute what's causing him to come off the medication and, and take the drugs. So, obviously it does, you know, worsen the symptoms, but that's not the...

Facilitator: That's not the whole picture.

Participant A: [it's not the] underlying issue, yeah.

Participant B: That's one thing that's really not recognized is the side effect of the drugs, very real, very bad, a lot of people don't want to live like a vegetable and, and, and that's a side effects of many of the [psychiatric] drugs.

This example illustrates how mental health, problematic mental health medications and illicit drug use are intimately interconnected.

Service users themselves discussed the role of drug use as a coping mechanism for mental health issues or as a way to reduce anxiety.

At first though, I had started having, realizing I was having abuse problems, it, actually it started back, way before I was even of age, like, training school. I started doing drugs when I was very young, because I was being abused and you know sexually and otherwise and be, and called a liar and whatever, and then I started slicing my arms and taking drugs just to hide, it was basically was to block out my mother and father because they were drunks, alcoholics, abusers, they didn't know how to even take care of themselves never mind the kids that they had in the house, which there was nine of us.

They're with men that beat them and do all kinds of stuff to them and they have to sneak out to do their drugs to cope with it

...well, like, my run with cocaine, my body just does not like that feeling and so it was, nothing beneficial, so like with marijuana it's a totally different you know calm feeling and I'm able to use it and it, it just takes my mind, like if you know, sometimes my mind's just working too much and it just slows me down and I can just relax and don't have to worry about things, like, I usually over dwell on things sort of, so I find that beneficial for me.

...well I use marijuana and, and what I find is that it makes me happy... like, [if] I'm not totally down in the dumps or anything like that, but if I'm sort of neutral and what have you is, I know I can sit in my back yard, puff a joint and, and you know after a while, I start to feel happy and that's something that my anti-depressants don't do and it gives me something to look forward to in the day. Like I look forward to relaxing and having a joint or two. And I don't get paranoid on it or anything like that, cause to me it's like, if the cops want to bust me, bust me, I don't care, I got nothing to lose.

Drug use can also help some feel integrated into a group. Service providers pointed out that different clients used drugs to help them feel like they belonged or were not different.

...Some kids will say to me, I don't know what else to do, I don't have any other options or no one's ever taught me how to entertain myself for hours. You know, a lot of the kids do it, you know, needing community, go with a bunch of kids, but, there are others who especially [feel this way]...we have a sort of a wave of kids who are street youth, but from war torn countries, who've been through, you know, post-traumatic stress disorder, so they have those symptoms, are working through them...When they're sort of longing for a sense of community or a belongingness, and they go out with some new kids they've just met, who are street youth and say,

you know, I don't want to do that, but I don't know what else to do. Often they'll say that. [voices agreeing] And so, ignorance or lack of what, whatever else.

...Or wanting to go out. I found that with some of the transgenders, who were new on the scene and weren't into drugs, but because they wanted to belong, they were soon mixing with the transgenders who work all night and support their drug habit that way, work on the street.

Service users were acutely aware of the downside that went along with the benefits they might receive from their drug use. Speaking about his illicit drug use, one service user said,

...sometimes I feel that it is an issue and other it times it definitely helps. Like, I, I'm an old speeder from way back. So, it kind of [goes] both ways sometimes, you know and it depends, it depends on my mental state. If I'm down and I use good meth amphetamines, [it] takes me in the other direction you know. There's only a few times that it's ever like, you know, but it's, because this is too strong I guess, I don't know...

...I'd sooner pop a pill or do something when it comes to killing pain. So, when the pain meds weren't working anymore, somebody turned me on to heroin and it was, say, all the pain rushed out, it was like I was eighteen years old again, not a pain in my body, I was hooked...when my workers comp wouldn't cover the heroin cost anymore, I went out and robbed banks. But I eventually got over that and I'm a, I'm not a bank robber anymore, so I've come out here [from prison] and I've tried to fit in...

For me I think it was a little bit of a self-delusion. I thought it was [serving] existential purposes at times, at others was just to try to, to be numb. I didn't want to think about problems in my life, regardless of if it was with my family or uh my to, handle my face my depression face on. That I found it made it much more difficult for me to cope with.

...But what I'm saying is, the reason I used it for and it does work to a certain extent, right? Is that it made me forget about my insecurities. And once you get to the point well, when you're on, in my own case, when I got to the point where I started feeling insecure while I was doing drugs, alright? Then I knew that that was my time to stop. Like, that was one good thing about me, I always knew when, when to stop. I knew my limits. I didn't let it run me over. I stayed on top of it and uh that's that.

One of the participants quoted above has recently had parole revoked for having traces of heroin and cocaine in a urine test. The individual has no provisions for

release for a few months. Many of the service users we spoke to have been jailed for drug-related offences or for testing positive to drugs. From a harm reduction approach, these things represent serious barriers to treatment. First, treatment may be avoided if drug testing is involved and that drug testing may lead to the revoking of parole. Second, there is no opportunity for mental health or drug use treatment in prison.

Access to mental health services that use a harm reduction approach is a central need of the people in the focus groups. Getting help for mental health issues or past abuse can be threatening. It is possible that drug use can help an individual start to deal with painful experiences. Abstinence-based mental health programs take away the "safety net" of drug use. For some service users, their drug use is an important component of their ability to deal with the root causes of their mental health issues.

When I use drugs, I use drugs to numb myself out, I'm dealing with issues, so I don't want to feel the emotions that go with it. [voices: that's right, ya]. Maybe I cannot really identify some of my emotions yet. I've been told not to cry. Be strong. Sit there and shut up. Just listen. Ok? And from that point of view, I have a lot of issues I'm dealing with. I, I don't even know how to say this, but, so I use drugs to numb myself, so I don't feel any pain, any emotion whatsoever. That's what I use, ok. And you've got to go [with it]...but, that's why I use. And I feel, the more I deal with these issues, the issues I'm dealing with right now, the less I want to stop using. Do you understand what I'm trying to say? And I am dealing with some of my issues, right now and I feel like I don't need to use that much. Where before I was in a \$900 a day habit...

Service providers and users alike point out that, for some, stopping their illicit drug use means taking away the only coping mechanism they have. To take this away without any supports, such as abstinence programs do, is to put the service user at risk of suicide, severe mental health problems or to push them away from trying to get any kind of help. The following conversation illustrates this issue.

Participant A: So to us it seems to be a case of that they [the client] were self-medicating for the schizophrenia, by using drugs that, even though they got treated, ten years ago as though the drugs and alcohol were the problem, it wasn't the problem. But they did go through the whole abstinence thing and they've been drop outs [from abstinence program]

and they've been fine. I think harm reduction would have worked a lot better for them, because they went through a process of, they had to go off all of their, their drugs and alcohol, then got treated for schizophrenia and all the medication. So there was a time period they had to be completely without anything.

Participant B: It's so hard on the body.

Participant C: Yeah.

Participant D: It's what you were saying about coping mechanisms, taking that coping mechanism away without putting things in place.

A service user shows how intricately drug use, mental health and the ability to cope with life are connected. Change one thing without taking into consideration the others can lead to great difficulty.

...Well, they want you to get off drugs, before they'll help you with your mental health and then nothing's holistic, nothing's together, you have to deal with one, each, they want you to pull it apart and put it into little safe little categories, doesn't work that way. Everything depends on something else, you know that your whole life can get ruined because you don't have carfare for something and there goes the rest of the year.

There is also some indication that working from a harm reduction approach may help to alleviate the stigma that service users experience from some service providers. As one service provider articulated, working from a harm reduction perspective allows the service provider to accept the client as he or she is.

There's one thing that you know I'm hearing around the room that I think is good and I think it's that avoiding the medical model idea that if the problem isn't eradicated, you're not ok. And you know that that's just such a healing thing for people and I really try to resist that even though we'd love for people to be off of drugs, but being with someone and just really accepting them and not feeling that tension at yourself, like as a service provider to feel that they need to move on because they pick that up so easily

Ideal Services

When asked about what their ideal service would look like, service users gave important insights into their needs. Some of the services involve reducing

stigma, especially in terms of having staff that are non-judgmental and believe what clients tell them.

...nobody judges you, or you don't have to feel embarrassed or, in any way...

Well, obviously, for me I would like to know that with the medical service especially, by stating who I am and what my history is, that I'm believed, that I'm not chastised, that I do get the service without feeling belittled...I want for a doctor to be honest and straight, and be forthcoming with me. And just treat me like an adult and if I say I don't share needles, then I need to be believed that I don't. I guess some people do lie and that makes things difficult for me, but I think, you know, people lie, part of the reason they do this is because they have been treated so badly, you know? So, that's a problem, I think that's a very big problem, I think people need to know that if they can be honest, then they're going to be treated ok, that it's not a scary thing, and that's not the way things are [right now]...

The section on service users experiences highlighted concerns they had with staff. These same concerns were reflected in comments about ideal services. For the most part, service users agreed that it would be ideal to have some staff that have lived experience.

Bt I truly believe, because you have some of them [service providers], that are twenty four, twenty five years old and I'm not being judgmental or mean or anything, but I mean, you know, mum and dad just bought them a 2002 car for graduation, they've never seen, you know, maybe a documentary, but they've never experienced anything such as like growing up with child abuse, with sexual abuse, on and on and on, with rape, with all these issues that lead to drugs and to the alcoholism and to the mental health issues, like all of that stuff leads to it, and mind you there are places for these [kinds of people]. But they need to have experience, being in school is wonderful, you know, and that's where people like us come in and really need to be there for the person that needs the support.

Part of the need for some staff with lived experiences comes out in discussions of the need for an advocate or guide to the mental health and drug use services system.

...I'd like to add to that ideal of let's say somebody who, you know, could co-ordinate all this and come from a background, who got his life straight, you know, her, her, his/her life straight, you know, it's your advocate, it's your friend. I think it's really good for us, because it gives us something to look forward to, you know, when finally I get my life straight I could work in this position and also those people like I would care, like if I got my life together and I'm working with people who are struggling to get their shit together, I would give a damn about what they're going through and I would understand what's going on a lot more than these people who just have come from technical backgrounds or a doctor or whatever, right, so and also, but they need to be given a lot of power within the organization. I mean I don't want to see them being peers or just basically bottom of the totem pole, so they've gotta be given a lot of power...what's the word I want, bureaucratic power, you know. I mean, the doctors and everything have gotta be able to listen to them if they say, no, this is what this person needs, this is what this person's gonna get. I mean, so that's what I'd like to see...

Service providers also saw a need for greater staff power in relation to medical doctors. One service provider felt that power struggles with medicine made her/his job more difficult.

My hobby horse, this is more I think from working in a hospital system is, and this will never happen, but what I think would help is for physicians, medicine, to become staff and not free agents. There's not a level playing field, there's always a power struggle and all sorts of dynamics that come out of that, that make all of our jobs difficult and if that were different, that would go a long way to changing how some of the things are done. We don't, as we're supposed to, work in partnership with medicine, we work in service of medicine.

Power was also an issue between staff with lived experiences and other service providers. Drawing on his own experience as a peer worker, one service user felt that peer workers were not respected.

You know and it's bullshit and it is and it's depressing and you try and say something and they're so burnt out, they don't want to hear it, you know, they don't want to hear, they don't care, and I know they don't, I've heard it, you know I've worked there. So, they you know, if you try and pull yourself together they've got these peer positions and stuff, but then they don't respect the peers and they don't listen to the peers, so that puts you down and that's depressing too, you know they won't even let you, oh there's so many things they won't let you do if you try to bring yourself up

and they just say that everyone's just a, a crabby whiner and you're just drug seeking when you're actually looking for some help and trying to understand anything.

Ideally, both service users and service providers would like service providers in a greater position of power relative to medicine. More service providers with lived experience would also be ideal, and it is important that they are respected and treated the same as other workers.

As with their experiences with services, service users also talked about the ideal of having a place to get away from drug use. This was often phrased in terms of safety and having a physical location away from drug activity. This could be in the form of a place to spend some time during the day engaged in activities that kept them safely away from thinking about their drug use. Some mentioned the need for a centre where users could stay for one to three nights to take a break from their drug use.

Participant D: Myself, I joined the, a good [social/neighbourhood] club and, you know, they show movies, watch tv all day, we can shoot pool all day if you want. You have to be fifty years of age or older to join, so, you know, that's where I go... That's where I go too, that's stay away from Sherbourne and Queen, I gotta, I stay out of that area... I stay out of that area I'm alright. As soon as I get down in that area this thing starts doing this [pretends to make hand shake] and...

Participant E: That's when you're stupid you mean.

Participant D: Ya. [laughter] You got it. You got it.

Participant E: [You get] that general rush?

Participant D: Ya... should I or shouldn't I [buy drugs]?

Another service user commented on the benefits of different kinds of activities.

There was an art program that just got you kind of socializing. I mean it's goofy, but I mean it was something to do, somewhere to go that you were safe and you know you weren't surrounded by the enemy, you know, so, so that was, that was helpful.

Service users incorporated the idea of a “safe” place to get away from drug use as part of their ideal service.

... So I think that the idea that you have there and if we could get a, like a, a medical or a situation like that, even a house like that for people that are stressed out or, or ill like we are, people that want to put their time and energy and hard whatever knowledge to whatever they want to do. That's maybe what they should do because these, the mental health place over there, it's not helping anybody.

A service user mentioned the Gerstein Centre as one model for a place to get a break and to rest.

Participant: We need more places like Gerstein Centre.

Facilitator: What's it about Gerstein that's useful?

Participant: Well, Gerstein Centre is run by non-medical people, it's a place where you can get away for a few days, it's a nice environment. It's just a big house. I think they call it a safe house. And there's a fridge there and they say walk in and help yourself and here's the kitchen, cook what you want and there just should be more places like it. And they say they don't have the funding. If they had the funding Covenant House did, they'd be able to do something about it.

Service users are not the only ones that want better access to and less judgmental treatment by medical doctors and/or psychiatrists that will listen and provide information about mental health medications and other treatments.

Service providers discussed that they need to take a more active role in terms of finding out about their clients' treatment and mental health medication side effects.

Facilitator: It raises another question, which is what, as folks working in the community, what do you folks see as your role...given you see these, heavy duty effects [of mental health medications]? How do you work with people around that? And...given that we're not medical people, do you give advice about the side effects? What do you do? Do you engage with the doctors? I'm kind of curious, what do people do?

Participant: I think engaging with the doctors is huge, because they're not as likely to ignore me or just minimize it. They're gonna actually answer my questions a lot more than a client who might feel intimidated or shy or nervous and used to getting fifteen minutes of service and then it's over, right? So, I'm

really learning that advocating is so, so key to getting better information, cause I don't always remember with everything, what the side effects. I can look it up, but I would rather just go to the doctor and say look. And then we don't always get that opportunity.

Overall, service users and providers were in agreement that more integrated services were needed. Service users need access to mental health support, including psychiatric services, as well as activities and support from those with lived experiences that help service users stay safe. This was referred to as "one-stop shopping" for getting help with mental health and drug use issues.

Well, you'd have psychiatrists and workers there, right where you go to pick up your stuff, right with the doctors. There's a team on you, it wouldn't just be one person, so one person can't take a dislike to you and sink your battleship, you can, you know, you, you've got two or three different people backing you up and you should be able to get, like these places they just hand it out. You can't, you can't see the doctor for any other problems, so you got a physical problem, you got a mental problem, you still gotta go elsewhere, and it's hard enough to get someone one place you know? And they [service providers] keep saying, no one comes back, no one comes back, boo hoo hoo. Well that's because they don't get much when they get there in the first place and I know that sounds like whining, but it is, it's depressing and you try and go back and you try and do something, but the services just aren't there, you know, you can't get help mentally there. You can like talk to a nurse practitioner or something, but you can't get medication if you need it for, for anything but for your drug problems and I just think it would be easier to deal with people's health issues and their, if they're drug users, by just doing everything in one spot...and not having you run all over the place like a mental case. And why can't they freaking dispense there? You know, just to make things less stressful, I mean it's stressful enough.

.... I've never had methadone so I don't know what that experience is all about, but it [one-stop shopping] would make things [easier]. I deal with psychiatrists at ARF and over depression and anxiety and that. But I agree with you, there should be more, like, the communication between you know all the services that you are using and getting, like if there were more, there's a huge lack of communication and that gets frustrating...

I think there should a lot more people in all of these agencies, I mean you're never going to have the perfect system, but all the agencies connected from the beginning to the end, from the time the person comes for help until...

Both service providers and users also identified a need for more access to information, both formal and informal, about mental health, drug, and other issues. The focus group moderators noted that in some of the focus groups, both service users and providers seemed to have a hunger for information that was implicitly expressed in the way they attempted to gather and share information with each other during the sessions. They wanted more information on the side effects of prescription drugs, and how illicit and prescription drugs interacted with each other. Service providers also expressed a need for more education and information related to broader issues that affect the populations they work with. One service provider used HIV medications as an example of the kind of information that would be beneficial to have.

I think because it's a shelter where people live and you're saying about having HIV, they have cocktail, they have medication. Well, you know, which certain foods which we should be knowing that are, are good or bad for certain medication that will help, that they shouldn't [eat] before [taking the medication]. That's what we try to do, you know, meaning, milk good, but maybe milk is bad. Maybe, you know what I mean, we have to learn a lot, we have to learn a lot if we're working with people.

Another service provider suggested that a network would be useful, where information could be shared among service providers, and service providers could refer a client to another provider with more knowledge of that client's issues.

A really good linkage system, so that you could go to a spot on the net and you could ask it the dumbest question possible and it could say, ok, call this person, they'll be able to help you with that answer or send your client over to there, because they're more competent than you are, something you know just sort of like, cause, I mean, there's too often that we're each stuck with like, ok, I don't know anything about this specific thing and I really should know, so often information that comes from the United States, often doesn't have the orientation that I'm even fond of anyhow, it's not really as helpful within the city. So more educational stuff is always of value.

Information sharing is an important component of harm reduction. But information sharing must be done in a non-judgmental way. The non-judgmental aspect of Harm Reduction encourages service users to tell service providers and

users' peers (who work and volunteer at some agencies) everything that happens in their lives in terms of their drug use. This may mean disclosing that they used an illicit drug and it is causing them side-effects. By disclosing information about their illicit drug use, service providers and peers are in better position to share crucial and useful information about illicit drugs, such as things the user can do to alleviate side-effects. This information may then be passed along by the service users to her colleagues and friends. Information sharing such as this is an important component of harm reduction, but it can only happen if there is trust and non-judgmental attitudes on the part of service providers.

Overall our findings point to the need for better mental health services combined with a harm reduction approach. Services that actively confront stigma and discrimination, that prioritize building trusting, respectful relationships, are integrated and flexible and client driven goals are consistently supported.

Conclusion

Our research highlights the potential and limitations of current services available for those with concurrent mental health and drug use issues. Based on what participants discussed with us, we believe there is a need to envision a program that fundamentally integrates community mental health with a harm reduction philosophy. Our results also suggest that integration is not enough. Integrated services that are provided in an authoritarian manner will not be accepted by this community (Bellack and Gearson, 1998).

Five specific recommendations concerning what the ideal service for those with mental health and drug use issues emerged from the comments of participants in our studies. These recommendations are:

1. Integration of harm reduction mental health service. This will involve Developing a program that does not stigmatize drug users or mental health consumer/survivors, that does not force them either to forgo treatment or lie about their drug use.

2. Service components: community based; outreach; flexible hours and location of services; counselling and community support; medical supports offered from a harm reduction perspective; advocacy and education to medical service providers; safe place for drug breaks
3. Staff Qualities: non-judgmental attitudes; staff with lived experiences; skills including counselling, system navigation and trained in harm reduction philosophy.
4. Education and Information: Effects of drugs, medications, interactions, and treatment options and alternatives; Development of harm reduction based counselling on drug use.
5. Community Development: Supporting the community to develop informal harm reduction based supports for this community; Education of ancillary services to promote working with harm reduction models

One of the more subtle findings from this research is that programs must more carefully consider the social networks of clients. Because it's difficult to find illicit drugs in the open market, illicit drug users are compelled to congregate and create a subculture where they can score, discuss shared realities, and generally support each other. This support system is predominant among the most marginalized illicit drug users. Within drug user networks, those who manage "to keep things together provide support for their less successful counterparts in many ways. It is important that programs for drug using clients to find ways to support the support systems of clients. This includes supporting illicit drug users who paradoxically needed the least support, but who provide support to others.

Since completing our research, we are now embarking on the second phase of our project. This is to design an actual service program, gain funding for implementing the program, then evaluating the program at various stages of the implementation. The service program we are designing will provide services that address both mental health and drug use issues from a consistently client directed and harm reduction perspective. Service users must be able to minimally access a linked network of services with shared values and philosophy.

This could involve the development of partnership agreements for service provision with community and medical service providers. This would require proactive outreach and education by community support staff to family physicians, psychiatrists and methadone dispensing physicians to encourage and advocate for these practitioners to work with a harm reduction perspective.

Our research suggests some concrete ways to develop our existing partnerships in South-East Toronto. In addition to the need for dedicated staff to provide community based harm reduction support and counselling we must enhance our existing partnership relationships with community health, mental health housing and legal supports. We can attempt to acquire and use sessional funds to pay medicals staff for consultation with program staff and service users. This is similar to a shared care model currently utilized by Alternatives, which is used to create a type of “one-stop shopping”. In this model psychiatric and community medical services are provided and extended beyond face-to-face and fee for service relationships to assist in providing direct education to service users and providers as well as toward providing flexible services and outreach in the community collaboratively with community support counsellors. This type of model would allow for us to meet the expressed needs of service users for client directed medical and psychiatric support when and where they are needed.

According to our findings staff must have a number of key characteristics including: counselling skills; lived experience as drug users and/or mental health consumer/survivors; a non-judgmental attitude; advocacy and system navigation skills. The community support model recommended by our findings also includes proactive outreach, long term engagement and supportive counselling.

There is a clearly identified need not only for an integrated service but for community development, education and systemic advocacy. Service users and providers could collaborate to create and deliver mental health/harm reduction education materials for the service user and provider communities. Education initiatives ought to include the community health, mental health and institutional care sectors and have an anti-discrimination focus. There is a need for accessible materials that outline the real risks of medication and drug interactions

and effects (similar to materials that have been developed for HIV/AIDS medications) as well as materials that explore alternatives to traditional treatment options for this community.

Our research has put us in a better position to further develop and assess a community support model that integrates harm reduction with mental health services. We believe it is necessary to design and evaluate a program in a way that is methodologically rigorous and includes the community at every stage of the study. The research presented in this report is a first step for improving the services available to and the lives of community members dealing with concurrent mental health and drug use issues. We must now acquire resources and funding to create a dedicated harm reduction/mental health program to provide service and create system changes as outlined above, and to evaluate the effectiveness of those changes.

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