Stigma, Discrimination



Substance Use

Experiences of people who use alcohol and other drugs in Toronto

An initiative of the Toronto Drug Strategy Implementation Panel

September 2010



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Executive summary

The Toronto Drug Strategy, which provides a comprehensive approach to alcohol and other drug issues, recommends the development of strategies to address stigma and discrimination toward people who use alcohol and other drugs. To inform the development of these strategies, the Toronto Drug Strategy Implementation Panel conducted focus groups to hear directly from people who use alcohol/other drugs about their experiences of stigma and discrimination. This report presents the results of that research project and makes recommendations for action.

The purpose of the research was to identify types and sources of stigma and discrimination experienced by people who use alcohol/other drugs, document the impact of these experiences, and identify strategies to help reduce their negative impacts. Six focus groups were held at a range of community-based agencies across Toronto, with a total of 60 participants. People who are homeless and/or otherwise living in poverty were the main focus of this study as they represent the most marginalized group of people who use drugs in our society.

Key findings from the focus group discussions include the following:

- Families are the most significant source of discrimination, with the most negative impacts.
- People are facing multiple forms of discrimination at the same time (e.g., related to their substance use, poverty, race, gender and age), and the compounded effect intensifies the severity of the stigma and discrimination.
- Negative self-esteem leading to self-stigma is the major impact of stigma and discrimination.
- Discrimination creates barriers to accessing services people need to stabilize their lives.
- Discrimination stops people from seeking help due to fear of how they will be treated.
- Peer support is an important coping strategy for people affected by stigma and discrimination.
- People need to be better informed of their rights to access services.
- Language about substance use needs to be more neutral and less judgmental.
- Putting a human face on the issue may promote more compassion and understanding.

Recommendations for action in this report to help reduce stigma and discrimination related to substance use include the following:

- 1. Strike a *Stigma and Discrimination Working Group* to implement the recommendations in this report.
- 2. Develop strategies to support/educate families of people with substance use issues.
- 3. Develop strategies to help people tell their stories of stigma and discrimination for use in anti-stigma initiatives.
- 4. Educate/train health care and other service providers on the complexity of substance use.
- 5. Develop peer/mentor initiatives to support people affected by stigma and discrimination.
- 6. Expand primary health care services in community services frequently used by people with alcohol/other drug issues.

Summary of recommendations

The ultimate purpose of this research project was to generate recommendations for action to be implemented as part of the Toronto Drug Strategy. Based on the key themes raised by people who participated in the focus groups for this project, the following actions are recommended:

- 1. The Toronto Drug Strategy Implementation Panel strike a *Stigma and Discrimination Working Group* to implement the recommendations in this report. The group should have a diverse membership that includes people who use or have used alcohol/other drugs, family members of people who use or have used alcohol/other drugs, and representatives from the areas of prevention, harm reduction, treatment and enforcement.
- 2. Develop strategies to support and educate family members of people with substance use issues including, for example, building on strategies used in the mental health field.
- 3. Work with a diversity of people from across the city that use or have used alcohol/other drugs to develop strategies to help people tell their stories of stigma and discrimination related to their substance use, including ideas for moving forward. And further, to promote use of these stories in a broad range of anti-stigma initiatives such as education and training.
- 4. Identify opportunities to provide training and education on the complexity of substance use issues to health care, social service, police and other professionals. For example, to build on training initiatives underway with emergency room staff to better support patients with substance use issues.
- 5. Develop and promote a range of peer/mentor initiatives to support people struggling with stigma and discrimination related to their substance use. Examples could include, for example, community programs in a central hub/location or integrating peer workers into hospital volunteer programs.
- 6. Advocate for and promote opportunities to expand delivery of primary health care services in community-based services frequently used by people who use alcohol/other drugs. This could include providing primary care clinics in harm reduction programs, drop-ins and shelters.

Introduction

The Council-approved, Toronto Drug Strategy (TDS) provides a comprehensive approach to alcohol and other drug issues for the City of Toronto. The strategy includes 68 recommendations for action, including recommendation 55, which calls on the City of Toronto, in partnership with the Centre for Addiction and Mental Health and community groups, to develop strategies to address stigma and discrimination toward people who use alcohol and other drugs.

The TDS Implementation Panel is an intersectoral leadership group that oversees implementation of the drug strategy recommendations. The Panel is concerned about the harmful impact of stigma and discrimination on the quality of life of people who use alcohol and other drugs. To help develop strategies to address these issues, the Panel wanted to hear directly from people who use alcohol/other drugs about their experiences of stigma and discrimination. This report presents the results of that research initiative, completed in spring/summer 2010, and makes recommendations for action.

Stigma and discrimination related to substance use

While there are various definitions, for the purposes of this report, the term stigma refers to negative attitudes towards people who have an attribute that deviates from what society deems to be "normal," and the term discrimination refers to negative behaviours towards people who deviate from those societal norms.¹ This report is concerned with stigma and discrimination experienced by people who use alcohol and other drugs. While the use of alcohol is legal and socially acceptable in our society, some use is not (e.g., chronic or chaotic use). The use of illicit drugs (e.g., cannabis, cocaine) is illegal and is viewed more negatively by society regardless of the reasons or nature of the use.

Research has found that people who use alcohol/other drugs are among the most stigmatized groups in our society.^{2 3 4} For example, a study by the World Health Organization found that illicit drug addiction ranked as the most stigmatized health condition; addiction to alcohol ranked fourth.⁵ Systemic types of discrimination experienced by people with substance use issues include reduced access to housing, employment and health care.⁶⁷⁸ A study comparing attitudes

¹ Centre for Addiction and Mental Health (CAMH). (1999) The Stigma of Substance Use: A Review of the Literature.

² Adlaf, E.M., Hamilton, H.A., Wu, F., & Noh, S. (2009). Adolescent stigma towards drug addiction: Effects of age and drug use behaviour. *Addictive Behaviours, 34*, 360-364. ³ Corrigan, P.W., Kuwabara, S., & O'Shaughnessy, J. (2009). The public stigma of mental illness and drug addiction: findings from a

stratified random sample. Journal of Social Work, 9(2), 139-147.

⁴ Ronzani, T., Higgins-Biddle, J., & Furtado, E. (2009). Stigmatization of alcohol and other drug users by primary care providers in Southeast Brazil. Social Science & Medicine, 69, 1080-1084. ⁵ Kelly, J.F., & Westerhoff, C.M., (2009). Does it matter how we refer to individuals with substance-related conditions? A randomized

study of two commonly used terms. *International Journal of Drug Policy, in press.* ⁶ Corrigan, et at. (2009), *ibid.*

of health care providers toward people with diverse medical and mental health conditions found that the most severe judgements and the highest rate of rejection were for people with substance use issues.⁹ Another study found that compared to people with mental health issues, people who use alcohol/other drugs were viewed as more dangerous, which led to increased social avoidance and isolation.¹⁰ The stigmatization of people with substance use issues is linked to a societal belief that they are to blame for their own behaviours and any resulting consequences.^{11 12 13}

Overall, there is limited research specific to stigma experienced by people who use alcohol/other drugs. There is also a lack of research about strategies to reduce stigma from the perspective of people who are stigmatized. More targeted research is needed in these areas. The current research project is intended to contribute to this knowledge base.

Purpose of the research

The purpose of this research project was to hear directly from people about their experiences with stigma and discrimination related to their substance use. This information will be used to help develop strategies to address these issues as part of implementing the Toronto Drug Strategy. The specific objectives of the research were to:

- 1. Identify the types and sources of stigma and discrimination experienced by people who use alcohol/other drugs;
- 2. Document the impact of these experiences of stigma and discrimination; and,
- 3. Identify strategies to help reduce the negative impacts of stigma and discrimination.

How the research was conducted

A subcommittee of the Toronto Drug Strategy Implementation Panel led this research project with policy and research support from the Toronto Drug Strategy Secretariat, which is the staff team in Toronto Public Health that supports implementation of the drug strategy. The Planning and Policy Professional Practice Unit in Toronto Public Health approved the research plan.

⁷ Link, B.G., Struening, E. L., Rahav, M., Phelan, J.C., & Nuttbroack, L. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behaviour, 38,* 177-190.

⁸ Luoma, J.B., Twohig, M.P., Waltz, T., Hayes, S.C., Roget, N., Padilla, M., & Fisher, G. (2007). An investigation of stigma in individuals receiving treatment for substance abuse. *Addictive Behaviours, 32*, 1331-1346.

⁹ Rozani, et al. (2009), *ibid.*

¹⁰ Rozani, et al. (2009). *ibid.*

¹¹ Adlaf, et al. (2009), *ibid*.

¹² Lavack, A. (2007). Using social marketing to de-stigmatixe addictions: a review. *Addiction Research and Theory. 15(5),* 479-492. ¹³ Ronzani, et al. (2009), *ibid.*

Qualitative data were gathered through focus groups with people who have experienced stigma and discrimination related to their use of alcohol/other drugs. Some quantitative data were also collected through a short information survey completed by focus group participants. The focus group questions and the information survey are attached in the appendix of this report.

A total of six focus groups were held at a range of community-based agencies across Toronto, with a total of 60 participants. The main focus of this study was on people who are homeless and/or otherwise living in poverty as they represent the most marginalized group of people who use drugs in our society. A pilot focus group was conducted to ensure validity and reliability of the questions and minor adjustments were made for future sessions. The agencies selected included shelters, drop-in centres, and treatment programs, and were located in both the inner core and outer areas of the city. Focus group participants represented a broad diversity of people, including men, women, youth, pregnant and parenting women, First Nations people, and minority ethno-cultural groups.

Focus group participants were recruited by designated staff at each agency. To be eligible to participate, people were to have used alcohol/other drugs in the previous six months, had experienced stigma and discrimination related to their substance use, and were capable of giving informed consent. Prior to the focus group, each participant completed a short survey that included demographic information on age, gender and housing status and area of residency in the city. The groups were co-facilitated by a staff member or peer worker at each of the participating agencies, and a Masters of Social Work intern who was part of the research team for this study. The groups ranged in size from five to 12 participants. Participants received a \$20 honorarium and two transit tokens for their time.

Responses to the focus group questions were transcribed from digital recordings, analyzed and grouped according to emergent themes. Information from the demographic surveys was collated and summarized.

Limitations

Limitations that may affect the validity of the findings include the ability to generalize results, self-report bias, and selection bias. The study included 60 participants, and it could be argued that the patterns of stigmatization and discrimination may not reveal a complete picture with this sample size. However, the recruitment of a broad diversity of people (e.g., men and women, adults, youth, people who live inside and outside the downtown core, First Nations communities, ethno-cultural communities) minimizes this limitation.

The data collected for this study was based on retrospective self-reports. The reliability of self-reports from drug users is often assumed to be poor. However, a study of injection drug users

(IDUs) assessed the reliability of self-reports of demographics, drug-related and sexual risk behaviours found that self-reports are generally accurate and reliable.¹⁴

Finally, because the participants were clients of the agency where the group was held and likely know the staff co-facilitating the session, it is possible their input may be affected. To help minimize this possibility, the Masters of Social Work intern, who was the lead facilitator and had no prior involvement with the agencies or their clients, made time at each session for participants to speak with her in confidence. A benefit of agency staff co-facilitating the session is that participants may have established a trusting relationship with them, which may increase their feelings of safety in the group. The participatory component of this research (the involvement of community agency staff in conducting the research) reflects accepted methodologies of community-based research. All participating agency staff were briefed on a standardized protocol for conducting the focus groups.

Results

A summary of the information collected through the demographic surveys and the key themes emerging from the focus group discussions are presented in this section of the report. Analysis of the results and recommendations for future action are discussed in the following section.

Who we heard from

As noted previously, all focus group participants had experienced some form of stigma and discrimination related to their substance use in order to be eligible to participate in the study. Out of the 60 participants, all but one voluntarily completed a short demographic survey, the results of which are described below.

Gender

The majority of focus group participants (63.7%) were male; 37% were female. Efforts were made to recruit people who identify as transgendered or transsexual, but they were not successful.

Age

As shown in Table 1, the majority of focus group participants were over the age of 40 (54%). One-quarter (24%) of participants were youth (defined as between the ages of 16 and 25). The remaining participants (17%) were in their thirties.

Table 1: Age Distribution			
Age Range	Number of Respondents	Percentage	
19 and under	3	5%	
20-24	11	19%	
25-29	3	5%	
30-39	10	17%	
40 and over	32	54%	

¹⁴ Goldstein MF, Friedman SR, Neaigus A, Jose B, Ildefonso G, Curtis R. (1995). Self-reports of HIV risk behavior by injecting drug users: Are they reliable? *Addiction*. Aug; 90(8): 1097-104.

Ethno-cultural identity

The majority of focus group participants (64%) identified themselves as "white or Caucasian." In addition, 20% of participants identified as First Nations/Metis/Inuit, 14% identified as "black," and 2% identified as "other," specifically African.

Source of income

As indicated in Chart 1, most focus group participants were living in poverty and relied on

some form of social assistance as their main source of income. Twenty-six participants were in receipt of Ontario Works, and 19 were in the Ontario Disability Support Program.

Eight people were employed, two were receiving pensions and seven individuals did not have any source of income. Three participants indicated "other" as their source of income, which included receiving money from



friends, sex work, and one unspecified response.

Housing status

As shown in Table 2, most participants (61%) lived in marginal or unstable housing

conditions, including shelters, motels, staying with friends or relatives, or living on the street. One individual had been in jail. Forty percent, or 21 of the focus group participants, had their own apartment or house, although the quality and security of this accommodation is not known. One person in this group had a supportive housing unit.

Area of residency

Participants were asked what area of Toronto they lived in. The majority of participants (63%) lived outside the downtown core with 25% coming from the Scarborough area, 12% from York, 12% from Etobicoke, and 8% from North York. A total of 37% of participants lived in the inner core of the city or "downtown."

Table 2: Accommodation in past three months * More than one answer can be selected		
Accommodation	Number of Respondents	Percentage
Own apartment/house	20	38%
Shelter/hostel	9	17%
Rooming/boarding house	8	15%
Street	5	9%
Parent(s)/relative's house/place	4	8%
Friend's place	4	8%
Supportive housing	1	2%
Hotel/motel room	1	2%
Jail/prison/correctional facility	1	2%

Experiences of stigma and discrimination

As mentioned, a main goal of this research project was to capture people's experiences of stigma and discrimination related to their substance use. Focus group participants shared a broad range of experiences about the types, sources and impacts of stigma and discrimination, which are summarized below.

Family and friends

The most significant source of stigma and discrimination with the most negative impact identified by focus group participants was family members. Participants described incidents of being cut off from family connections, a lack of support, and negative judgements not only about their behaviour but also about their character.

"My brother doesn't want to talk to me because I've used [drugs]."

"I'm outcast from the family because I'm an alcoholic."

"Your mom, your dad, your brother, your sister... they say you're a worthless piece of crap, and they want nothing to do with you."

"My family, that's where I get it all from. I'm a whore, I'm a thief, I run the streets, I'm a crackhead, I'm dirty, I'm no good."

For some participants, family members were seen as the most discriminatory because they were the only people in their lives aware of their history of substance use.

"I get a lot, mainly from my family, because I don't tell other people what I do."

"I don't look like a crackhead, do I? I've been smoking it for 20 years. I don't get discriminated by cops because I don't look it, I don't play that part. It's my family, because they know. They disowned me."

Friends were another source of discrimination raised by focus group participants, specifically people they knew before they started using alcohol/other drugs and whose friendships they had lost because of their substance use.

"Friends leave you, 'cause once they find out you smoke, and they don't smoke they're like 'OK, your not in our clique no more."

Community and society

A common theme throughout the focus group discussions were experiences of stigma and discrimination by "everybody, everywhere." Participants felt that discrimination against people who use alcohol/other drugs is deeply ingrained in our society, that it is socially acceptable, and therefore, cannot be eliminated.

"Discrimination is everywhere when it comes to drugs. You walk down the street and people judge you."

"Everybody discriminates – the whole world."

"Society is very judgmental of us."

Some participants expressed a sense of hopelessness that they could have the same opportunities and advantages as other people in the community.

"You don't even bother applying for a lot of things, because you just know it's not worth the trouble. People are not going to give you a chance."

Health and social service providers

Another major source of discrimination raised by focus group participants was health care providers, including hospital and primary care physicians, nurses, and hospital security staff. Participants felt that their medical concerns were not taken seriously, and that physicians believed they were only there to get drugs.

"[---] hospital has labelled me as narcotics seeking. It's on file there, so I don't bother going there anymore."

"They won't even give you a pain killer because they take one look in your eyes and say "Oh, you're a druggie."

Some participants described being denied access to health care and receiving poor treatment from hospital staff.

"If I walked into a doctor's office trying to get a new family doctor, they'd say "Oh, we're booked". Meanwhile, someone who's already a patient there just told me that he's taking patients."

"It's hard to get a doctor when you're a drunk."

"I slashed my wrists in the emergency room. They sewed me up, threw me out on the side walk and told me never to come back, even if I was dying."

"I've been thrown out of the hospital. I've been thrown out in a hospital gown by security guards."

Because of the negative experiences participants had in the health care system, some people stopped trying to use these services.

"I don't go to hospitals."

"I stopped getting health care because of it [discrimination]."

"I should have a cast on my hand now, but I don't."

Participants also talked about discrimination by staff in emergency shelters and social assistance programs (e.g., Ontario Works and the Ontario Disability Support Program). Some participants said they did not trust shelter workers and were not comfortable talking to them about their issues. Participants felt these workers had significant power over their lives as they controlled their access to basic needs such as income and shelter, and therefore, discrimination from these sources had a particularly negative impact.

Law enforcement

Another common theme raised in the focus group discussions was discrimination by police officers. Some participants felt they were unfairly targeted or "profiled" by the police because of their history of alcohol/other drug use.

"When I walk outside, the police jack me up because I'm a drug user. It's not right."

"When the cops pull me over they think I'm guilty when I'm not guilty of anything."

"Sometimes when I'm in the park drinking beer some big cop comes up to me, kicks the bag, and says, "Where's the crack?"

Landlords/housing providers

Participants also raised the issue of discrimination by landlords and housing providers that they felt was related to their substance use. Participants described difficulties in finding and maintaining stable housing because landlords would either reject their application for housing, or later evict them because of their substance use.

"When you have alcohol and drug problems, it's hard to get housing...unless you can get it by doing paper work only – if they don't see you."

Teachers and employers

Some focus group participants identified teachers as a source of discrimination in their lives because of threats of suspension or expulsion from school if they continued their substance use. Participants felt a better approach would be for principals and teachers to talk with youth about why they are using alcohol/other drugs rather than disciplining them or taking a hard line approach.

"Teachers should probably do counselling to find out why we are using [drugs]."

Several participants had been employed in the past but were dismissed by employers because of their substance use.

"I lost a job because my boss didn't like weed but I wouldn't smoke when it was time to work."

Additional forms of discrimination

A key theme that emerged across the focus group discussions was that people experienced multiple forms of discrimination, including classism, racism, sexism and ageism, in addition to the discrimination they felt was specifically related to their substance use.

As noted, the majority of focus group participants were living in poverty with either Ontario Works or the Ontario Disability Support Program as their source of income. Some participants felt the discrimination they experienced because of their substance use was heightened because of their poverty.

"A lot of people who [use drugs] are disadvantaged, in a bad position. Why are you cracking down on these people? They don't need stress from people judging them."

Participants also felt there was a double-standard with respect to income, highlighting the fact that upper and middle class people also use drugs and yet participants felt these individuals did not experience the same levels of discrimination.

"I know more lawyers and judges that snort coke that you could shake a fist at."

Some of the racialized¹⁵ focus group participants felt that the stigma and discrimination they experienced related to their substance use was more severe because of their race or ethnicity. Some of these participants felt they were penalized more harshly than Caucasian/white people for their substance use, and were unfairly targeted or "profiled" by police.

¹⁵ Racialization refers to people who receive or experience different treatment or denial of rights or privileges by individuals and institutions because of their race.

"Sometimes being black, you can't be 'chillin' with people on the street. 'Cause on my street, if I'm seen chillin' with certain white people the cops would just pull me aside and see if I'm selling crack or something."

"I'm Native and they assume I have an alcohol problem. They figure I'm a drunken Indian, which is pretty awful."

Some of the women in the focus groups felt that their gender was an issue with respect to the level of discrimination they experienced. These participants felt that stigma and discrimination was "worse for women" and that it increased when they became pregnant and had children.

"If you're pregnant and smoking drugs, people say 'are you stupid?""

"People look at you like you're the worst mother in the world."

Discrimination by child welfare workers was highlighted as a key source of discrimination by these women who felt that the workers did not understand substance use issues. Some women felt this lack of awareness influenced the types of protection orders they received. For example, women were frequently required to attend drug treatment but doing so did not necessarily decrease the involvement of the child welfare system.

"I don't think they [child welfare] really understand what we're going through. They don't really understand what type of life we have or what we've been through."

"There are people who are trying to make a change, who are doing everything in their willpower to stay better. They are trying to be good parents and they deserve their children, and they still can't get them because [child welfare] thinks they're not doing enough. When is it ever enough?"

Finally, participants at either end of the age spectrum felt that their age affected the intensity of stigma and discrimination they experienced.

"A lot of younger people get in trouble for stuff like drugs way easier."

"The older the person is that is using [drugs], the more they're discriminated against."

Negative self-esteem and self-stigma

The most common impact of stigma and discrimination raised by focus group participants was poor self-esteem. People talked about feelings of worthlessness and powerlessness over their lives, and how they had come to believe the negative opinions that other people had of them because of their substance use. The internalization of the negative views of others is referred to as "self-stigma."

"Once they put it in your head so many times you hear it over and over. It's like a recording in your head; it won't stop. Like, 'I'm a crackhead, I sell my body.' Once you keep hearing this recording over and over, this is what you start to believe. You start to believe this is what you are, and you're worthless."

"Sometimes I think I'm a crackhead and that's all I am."

"Worthlessness - I suffer because of what I do to get drugs."

"It [discrimination] makes me feel powerless sometimes. It makes me feel worthless. It makes me feel stupid."

Some participants tried to rise above the stigma and see themselves more positively.

"It impacts your self-esteem. You get treated like a piece of shit all the time, and you're sitting there wondering why. I'm a fairly educated guy. I worked my way through the work force and ended up making over \$80,000 one year. Why am I getting treated like a piece of shit?"

"I'm better than that, and I'm a good person. I can do better than this."

Coping with stigma and discrimination

Focus group participants were also asked what they did to help cope with the stigma and discrimination they experienced as a result of their substance use.

Increase their substance use

The most common strategy used for coping with the negative feelings associated with stigma and discrimination was to continue or to increase their use of alcohol/other drugs in an effort to "numb the pain."

"I use more drugs and alcohol to numb the pain."

"You run and you use, that's how you cope with it."

"I cope by getting high."

Seek support from peers

The second most frequently mentioned way of coping was to turn to other people who use alcohol/other drugs as a source of support. Participants felt that because their peers had similar experiences that they would be less judgmental and better able to understand what they were going through.

"I find comfort in confiding in other people that use."

"I can talk to my dad, because he smokes [marijuana]."

"I have more family on the street than I feel I have with my own relatives."

Seek support from helping professionals

While some focus group participants had difficulty trusting workers (e.g., child welfare workers, emergency shelter staff), they did say staff and counsellors that dealt specifically with substance use issues were a source of support. Participants identified harm reduction workers and staff in drop-in centres most frequently as workers they could turn to for support.

"I talk a lot to harm reduction people. If I have a problem, I can talk to them."

Participants also said they were more likely to seek support from a worker who had a history of alcohol/other drug use rather than someone they felt only had an academic understanding of substance use issues. A common theme through the discussions was the difference between "real life experience" and "textbook learning."

"Textbook people who haven't been there, they don't know anything."

"When you have a relapse, [workers] they hold it against you. I mean maybe some are able to understand what we're going through, but some go through the books and they don't really understand what type of life we have or what we've been through."

Indifference

Indifference was a strategy used by some participants to cope with the negative impacts of stigma and discrimination. People said they ignore or dismiss what other people said or how they acted as not important or relevant to them.

"I just walk away from the situation and brush it off."

"I just ignore it. I look where it's coming from."

Advocate for their rights

The least common coping strategy mentioned by focus group participants was advocating for their rights such as by making an official complaint against the individual or organization that was being discriminatory. But for some participants, this strategy was helpful.

"If I had a real problem with an establishment or something, I'd just find the best advocate I could because everybody's got a boss, and just keep going up."

"Some people file complaints because the police were constantly harassing them... you could file a complaint to your local police division."

Some participants raised concerns about taking this type of action including a fear that it would increase the discrimination or that the complaint would not be taken seriously. Specific examples included, individuals feeling that discrimination by police increased after a complaint was made, and being denied access to an emergency shelter after a complaint was made against a staff person in that shelter.

Ideas for reducing stigma and discrimination

Another important goal of this research project was to hear from people about what strategies they think could help reduce or eliminate stigma and discrimination related to substance use with a view to using this information help develop future Toronto Drug Strategy initiatives.

Humanize people with substance use issues

Humanizing people who use alcohol/other drugs was the most common suggestion for countering stigma and discrimination. Participants felt that they are viewed as "non-human," and this enabled other people to feel justified in discriminating against them. Participants wanted people in the community to understand that they are "human beings with feelings" and that discrimination affects them as negatively as it does anyone else.

"We could be your mother, your daughter, your sister, your brother, your nephew, your niece, your whatever. And what if it were? How would you feel? People have feelings. We have feelings."

"Treat me the way I would treat you. Because I have a drug problem doesn't mean I'm a bad person. It just means I'm a person who is sick and needs help."

"We're human, we're just like them... we just have a disease."

"Have people who use drugs go out and talk to people so they can see what it's like to have an addiction - that we are normal like everyone else."

Education and training

Focus group participants felt that educating professionals about why people use alcohol/other drugs could help lessen stigma and discrimination. They felt that if workers were better informed they would be more understanding of the varied and complex reasons for substance use. Some participants felt that anyone who works with the general public should be trained about this issue. Government employees (e.g., staff in the Ontario Disability Support Program and Ontario Works), emergency shelter workers, health care professionals, pharmacists, child welfare workers, law enforcement, and even staff in beer and liquor stores, were identified by participants as needing more education and training.

"Educate them [workers] that people use [drugs] for many different reasons."

"Drug use stems from something, and it supplements something."

"My parents drank when I was a kid. I was around domestic violence and stuff."

"I think they need to be informed about harm reduction."

Participants also suggested educating the general public about the roots of substance use through advertising campaigns. One idea was to develop a campaign to counter the National Anti-Drug Strategy public education campaign, one that would provide information that is fact-based and not fear-based.

Nothing can be done

A theme raised in every focus group session was a sense of hopelessness that anything could be done to change, reduce or eliminate stigma and discrimination against people who use alcohol/other drugs. Some participants felt that this type of stigma and discrimination is ingrained in every aspect of our society and that nothing can be done to change it.

"To be honest with you, their opinion is their opinion. I don't think any of that will change."

Discussion and recommendations

The purpose of this study was to hear from people about their experiences of stigma and discrimination related to their substance use, including the types and sources, impacts, coping strategies, and ideas for addressing this issue. The study focused on people who were homeless or otherwise living in poverty as they are among the most vulnerable and marginalized in our society. The 60 people who participated in the focus groups represented a broad range of age, gender, geography of the city, and to some extent, ethnicity. This section of the report discusses the main themes that emerged from the research results.

Families are the most significant source of discrimination

A key finding of this research project was that family members were the most significant source of discrimination for people with substance use issues, with the most negative impacts. Focus group participants spoke about discrimination from many other people, including health care providers, social service workers, police, landlords, teachers, and the general public, but for them the most painful experiences involved their families.

"Why don't the people I love support me? Why aren't they there? I have these strangers, these counsellors, and they try and help me but they don't know me. They don't love me and know where I'm coming from. I want the people who love me and the people I love to help me."

Participants described incidents of being cut off from their families, a loss of support and care, and being subject to negative and degrading labels and judgements. The estrangement and alienation from their families had a particularly negative affect on their self esteem and self worth. It also likely affected their resiliency and ability to cope with the range of issues related to their substance use issue. Family connection and support is a critical aspect of resiliency, especially for young people. One participant talked about how a lack of family support affected their goal to stop using drugs.

"My family make it easier for me to relapse because they're not supportive, and because they put me down in such a way."

It can be challenging for families to support a family member with a substance use issue, especially without access to services and supports to help them do so. In Vancouver, a family support network called *From Grief to Action* has worked for many years to support families who have a loved one with a substance use issue as well as to advocate for broader, evidence-based action to expand prevention, harm reduction and treatment options.

People are facing multiple forms of discrimination

Another key finding of this study was that people are experiencing many types of discrimination at the same time and the compounded effect of this intensifies the severity of the stigma and discrimination. Participants talked about how their age (both young and old), gender (especially women who are mothers), and poverty added to the level of discrimination they experienced because of their substance use. Discrimination was also increased for racialized participants who felt they were treated more harshly than Caucasion/white people because of their race, especially by law enforcement.

It may be hard for people to determine the exact source of their discrimination. Is it because of their homelessness, their poverty, their age, their substance use, or some combination? In this study the focus was on the individual's experiences and perceptions of how they were treated by other people. It is possible that some of the behaviour of others may not have been intended as discriminatory. For example, the child welfare workers who were imposing strict protection orders may have felt justified in their role as protecting the child. However, stigmatizing behaviour is not a motivator for positive change. There are successful strategies and programs that focus on keeping children safe while also being supportive and empowering to the mother.

In Canada, people are protected from discrimination based on "*race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted"* under the Human Rights Act. For many, the issue of substance use extends beyond the realm of health care and is now being framed as a human rights issue. Among the people who participated in this research project, there were very few who asserted their "rights" by lodging complaints against the individuals or organizations discriminating against them, in part because they felt this only made the discriminatory behaviour worse. Strategies that help people to assert their rights can help empower them and lead to better self esteem and a sense of confidence that they can take action to improve their lives.

Negative self-esteem is the major impact of stigma and discrimination

It was clear from participants in this study that the stigma and discrimination they experienced related to their substance use had an impact on all aspects of their lives. Impacts included the quality of their relationships and their ability to access services, resources and opportunities in the community. However, the most severe impact of stigma and discrimination was negative self esteem. Participants frequently shared feelings of worthlessness, powerlessness, and hopelessness.

"Once they put it in your head so many times you hear it over and over. It's like a recording in your head that won't stop. Like, 'I'm a crackhead, I sell my body.' Once you keep hearing this recording over and over, this is what you start to believe. You start to believe this is what you are, and you're worthless."

Once people internalize the negative opinions of others (self-stigma) it can cause significant damage to their self esteem and well-being. In one study of men who use alcohol/other drugs, self-stigma was found to have a devastating impact.¹⁶ The negative experience of being stigmatized was so powerful that it countered any benefits these men were receiving through their substance use treatment. Stigma also has also been shown to have a profound impact on the ability of individuals to have meaningful intimate relationships.^{17 18}

The Mental Health Commission of Canada highlighted the importance of "direct testimony from people who are, or have been 'there'" as part of successful anti-stigma initiatives. Allowing people an opportunity to speak about their experiences with stigma and discrimination in a way that is welcomed and respected is one way to help improve self esteem as well as to get them involved in positive change. Involving people who use alcohol/other drugs as spokespeople is recognized by the Mental Health Commission of Canada a key part of any anti-stigma strategy as is highlighting the positive contributions people with substance use issues make to their local communities.19

Discrimination creates barriers to accessing services

Another significant impact of stigma and discrimination raised by study participants was that it created barriers for them in accessing important health and social services. Participants talked about receiving poor treatment from some service providers, including income assistance and emergency shelter staff, which in turn affected their ability to meet basic needs such as income and shelter.

Barriers to accessing health care services was another key issue highlighted in this study. Other research has found similar results. One study found that substance use was the most "moralized" condition judged by primary health care providers because people who used alcohol/other drugs were viewed as responsible for their own health issues.²⁰ Another study of interactions between health care providers and patients with alcohol/other drug issues found that patients experienced "exclusion, rejection, blame, or devaluation," and in some cases clinical decisions were influenced by negative social judgements and generalizations about these patients.²¹

The alienation that people who use alcohol/others drugs experience and the internalization of the belief that they are marginal members of society are associated with poor health.²² Therefore, reducing stigma and discrimination is an important strategy for improving the health of people who use alcohol/other drugs, both in their ability to access health services, and in their belief that they can be, and deserve to be, healthy.

¹⁹ Kirby and Keon, (2006), *ibid.*

Dependence, 88, 188-196.

¹⁶ Link, et al. (1997), ibid.

¹⁷ Corrigan et al. (2009), *ibid.*

¹⁸ Luoma et al. (2007), *ibid*.

²⁰ Rozani, et al. (2009). *ibid*

²¹ Henderson, S., Stacey, C., & Dohan, D. (2008). Social stigma and the dilemmas of providing care to substance users in a safetynet emergency department. *Journal of Health Care for the Poor and Underserved*, 19, 1336-1349. ²² Ahern, J., Stuber, J., & Galea, S. (2007). Stigma, discrimination, and the health of illicit drug users. *Drug and Alcohol*

Discrimination stops people from seeking help

Another serious impact of stigma and discrimination highlighted in this research project was that it stopped people from seeking or using the services that could help them to stabilize and improve their lives. Other research has found that stigma is a major reason people do not seek help to reduce or stop their substance use.²³ Further, people who see themselves as responsible for their own issues (a common discriminatory message) are less likely to seek help.²⁴ People with alcohol/other drug issues often have multiple health and social issues for which they may need help coping with or overcoming. However, if people do not even try to use health and social services because they are afraid of how they will be treated, an important resource for stabilizing their lives has been lost.

Related to this issue, the most common strategy used by focus group participants to help cope with the negative impacts of stigma and discrimination was to increase their use of alcohol/other drugs as a way to dull or numb the pain they were experiencing.

"Discrimination leads to more use, not to people quitting."

It is unfortunate that the stigmatization of people who use alcohol/other drugs is for many perpetuating their substance use as well as to preventing their seeking help. In that regard, implementing strategies to reduce stigma and discrimination, and that focus on helping people to feel worthy of receiving help and support, are important.

Peer support is an important coping strategy

In addition to finding ways to reduce or eliminate stigma and discrimination, strategies are needed to help people cope with the negative impacts they are experiencing now. Focus group participants highlighted the important role that peers play in helping them to cope. Participants felt that other people who had been through similar experiences were more likely to empathize with what they were going through, and less likely to judge them for their substance use.

In this context, peers include friends or acquaintances who also use alcohol/other drugs as "peer workers" who are clients paid by agencies to help deliver programs. Peer workers are often used in harm reduction and other programs as they have been shown to be effective in helping to open conversations and lend support, which provides an important link between people who use drugs and health and social service services.^{25 26} Community outreach, in which peers provide education and support, is recognized as an effective strategy to reach people who use drugs and reduce risky behavior related to disease transmission.²⁷

²³ Kelly et al. (2009), *ibid*.

²⁴ Corrigan et al. (2009), *ibid.*

²⁵ Latkin, C.A., Forman, V., Knowlton, A., and Sherman, S. (2003). Norms, social networks and HIV–related risk behaviours among urban disadvantaged drug users. *Social Science & Medicine, 56*, 465-476.

²⁶ Kerr, T., Small, W., Peace, W., Douglas, D., Pierre, A., & Wood, E. (2006). Harm reduction by a "user-run" organization: A case study of the Vancouver Area Network of Drug Users (VANDU). *International Journal of Drug Policy*, 17, 61-69.

²⁷ Coyle, S.L., Needle, R.H., and Normand, J. (1998). Outreach-based HIV prevention for injection drug users: A review of published outcome data. *Public Health Reports*, 113 (1), 19-30.

Put a human face on the issue of substance use

Some participants felt that nothing could be done to eliminate stigma and discrimination because it was so ingrained in our society. Certainly, the illegal status of some drugs has contributed to a negative view of this type of substance use along with social and political perspectives. Research has found that the increased criminalization of illicit drugs is associated with an increase in the stigmatization and discrimination of people who use drugs.²⁸

"We could be your daughter, your sister, your brother, your nephew, your niece, your whatever. And what if we were your brother, or your sister or your mother? How would you feel? People have feelings, we have feelings?"

However, the most common strategy suggested by participants to help reduce stigma and discrimination was "humanizing" people who use alcohol/other drugs. Focus group participants felt that if society better understood the complex reasons that people use alcohol/other drugs, they may be less judgemental, and, therefore, less discriminatory towards them.

Putting a more realistic "mainstream" face on substance use issues is a recommended approach for reducing stigma and discrimination.²⁹ This approach has been used, for example, by in Centre for Addiction & Mental Health's in their Transforming Lives Awards. The Mental Health Commission of Canada has highlighted the lack of a powerful voice from the addictions field to profile this issue as well as stressing the importance of involving people who use alcohol/other drugs as spokespeople in anti-stigma strategies.³⁰

Train and educate professionals about substance use

Another strategy raised by focus group participants was to provide more training and education about substance use issues to anyone working with the public, including social service workers, shelter workers, health care providers, law enforcement, pharmacists, and even people who work in beer and liquor stores. Participants felt they would be treated better by service providers if those workers increased their knowledge about the complexity of substance use.

Providing evidence-based education on substance use issues, including models of prevention, harm reduction and treatment is recognized as a way to reduce stigmatizing attitudes.³¹ In a review of key aspects of successful anti-stigma initiatives, the Mental Health Commission of Canada found that educating people about the realities of substance use, including engaging them at an emotional level is an important piece.³²

²⁸ Ahern, et al. (2007), *ibid*.

²⁹ Lavack, A. (2007). Using social marketing to de-stigmatize addictions: A review. *Addiction Research and Theory. 15(5)*, 479-492.

³⁰ Kirby and Keon, (2006), *ibid.*

³¹ Rozani et al. (2009), *ibid.* ³² Kirby and Keon, (2006), *ibid.*

One specific issue raised by focus group participants related to health care providers was pain management for people with substance use issues. Participants talked about being accused of "drug seeking" when going to a hospital or other health care facility, and of not having their pain management issues dealt with appropriately.

"My hand is broken and they're telling me to take Advil."

People with substance use issues have the same right to health care as the rest of the population, including treatment for pain. There are other less addictive pain management strategies that can be used instead of narcotics. Health care providers should be trained in these and other strategies specific to people who use alcohol/other drugs to ensure that people are not left to suffer.

Educate the public about substance use

Stigma and discrimination from the general public was a common experience for participants in this study. Participants felt there was social permission to stigmatize people who use alcohol/other drugs and that these attitudes will be difficult to change. One strategy for educating the general public about substance use issues suggested in the focus groups was the use of advertising campaigns. Education campaigns on their own are not effective in changing behaviour or attitudes.³³ However, other research has found that comprehensive social marketing campaigns do have a role to play.³⁴ Social marketing is defined as "seeking to influence social behaviours in order to benefit a target audience and society in general... the main focus in social marketing is determining what people need and want, rather than persuading them to buy into a pre-existing notion."35

Social marketing strategies can include public service announcements, billboards, mass media messages, media events, and community outreach. However, to be effective, they should also include partnerships with substance use agencies, non-governmental organizations, government departments, medical organizations, service clubs, media outlets, corporate sponsors, etc. Advocacy is also an important component, for example, advocating with policy makers to eliminate polices that discriminate against people who use alcohol/other drugs.

The review of effective anti-stigma initiatives conducted by the Mental Health Commission of Canada also highlights the need for a multi-pronged approach that is targeted to specific audiences (as opposed to everyone at the same time), sustained over a substantial period of time, and that reflects local community circumstances.³⁶

 ³³ Benard, B. (1986). Characteristics of effective prevention programs. *Prevention Forum*, Vol.6(4), 57-64.
³⁴ Lavack, (2007), *ibid.* ³⁵ Lavack (2007), *ibid.* ³⁶ Kirby and Keon, (2006), *ibid.*

Change our language

Words are important. If you want to care for something, you call it a flower: if you want to kill something, you call it a weed." – Don Coyhis

In this research project, focus group participants talked about the power of negative and degrading labels to affect their self-esteem as well as their treatment by other people. Words like "crackhead" and "whore" were used to label and degrade individuals, and some participants even came to refer to themselves in these terms. One study that focused on language used by addiction treatment providers found that when individuals were referred to as "substance abusers" they were seen as "perpetrators" engaging in wilful misconduct, and more punitive interventions were recommended. When people were said to have a "substance use disorder" they were viewed more as "victims" of a biomedical process, and treatment-based options were recommended.³⁷ Therefore, even among highly trained clinicians, variations in language can directly impact the type of treatment that is offered to the person seeking help.

There is no medical diagnosis other than alcohol/other drug use to which the term "abuse" is applied as a diagnostic term.³⁸ This language does not support people with substance use issues to improve their quality of life or to improve their self esteem. It also speaks to a totality of identity that is neither fair nor accurate. People are more than their substance use, they are people first, and they are also mothers and sons, musicians and artists, students and teachers, etc.

Use art to reduce stigma

Although it was not mentioned by the focus group participants in this study, another strategy to reduce stigma that was found in the literature is the use of arts-based initiatives.³⁹ These projects help to reduce the stigma that participants experienced because it helps them make sense of the world they live in, promote social interactions, and reduce powerlessness through the validation of their own experiences.

The rationale for using arts-based interventions is that they "challenge the effects of stigmatization and foreground the experience of people who have been historically silenced."⁴⁰ Art is also a way for people to explore their experiences of stigma and discrimination, including self-stigma, using a variety of creative mediums.

³⁷ Kelly, J.F., & Westerhoff, C.M., (2009). Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms. International Journal of Drug Policy, in press.

³⁸ White, W., Kelly, J.F. (2010). Alcohol/Drug/Substance Abuse: The History and (Hopeful) Demise of a Pernicious Label.

Commentary. ³⁹ Paivinen, H., & Bade, S. (2008). Voice: Challenging the stigma of addiction; a nursing perspective. *International Journal of Drug Policy, 19,* 214-219⁴⁰ Paivinen, et al. (2008). *ibid.*

Build on existing efforts

The Toronto Drug Strategy Implementation Panel is not the only group concerned with the impact of stigma and discrimination on people who use alcohol/other drugs. For example, the Centre for Addiction and Mental Health (CAMH) has a number of initiatives aimed at reducing stigma including the CAMH Foundation's Transforming Lives Awards that profiles the successes and contributions of people with mental health and/or substance use issues. Action has also been taken through the provincial Methadone Maintenance Task Force to help reduce stigma and discrimination experienced by people who are receiving methadone treatment in Ontario.

The Mental Health Commission of Canada has identified the need for a systemic effort to reduce stigma and combat discrimination as essential to improving the situation of people living with mental health issues.⁴¹ In 2008, the Commission initiated a 10-year national campaign to reduce stigma and discrimination experienced by people living with mental health issues. However, it is not clear how substance use issues will be addressed in this campaign. This is an area for further advocacy, especially as it relates to the funding of stigma and discrimination issues.

Also in 2008, the National Treatment Strategy Working Group identified stigma and discrimination as serious impediments to the well-being of people with substance use problems.⁴² In their report, the Working Group recommended "the development, implementation and evaluation of an evidence-based comprehensive strategy … to increase awareness and understanding and thereby reduce stigma related to problematic substance use."

In Ontario, the Ministry of Health & Long-Term Care is developing a Mental Health and Addictions Strategy, and stigma and discrimination is identified as a key area for action. This strategy is expected to be released in fall 2010 and there may be opportunities to link the work of the Toronto Drug Strategy with actions recommended in this provincial strategy.

Recommendations for action

The ultimate purpose of this research project was to generate recommendations for action to be implemented as part of the Toronto Drug Strategy. Based on the key themes raised by people who participated in the focus groups for this project, the following actions are recommended:

1. The Toronto Drug Strategy Implementation Panel strike a *Stigma and Discrimination Working Group* to implement the recommendations in this report. The group should have a diverse membership that includes people who use or have used alcohol/other drugs, family

 ⁴¹ Kirby, M. J., and Keon, W.J. (2006) *Out of the Shadows at Last: Highlights and Recommendations.* Standing Senate Committee on Social Affairs, Science and Technology.
⁴² National Treatment Strategy Working Group. (2008). *A Systems Approach to Substance Use in Canada: Recommendations for a*

⁴² National Treatment Strategy Working Group. (2008). *A Systems Approach to Substance Use in Canada: Recommendations for a National Treatment Strategy*. Ottawa: National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances in Canada

members of people who use or have used alcohol/other drugs, and representatives from the areas of prevention, harm reduction, treatment and enforcement.

- 2. Develop strategies to support and educate family members of people with substance use issues including, for example, building on strategies used in the mental health field.
- 3. Work with a diversity of people from across the city that use or have used alcohol/other drugs to develop strategies to help people tell their stories of stigma and discrimination related to their substance use, including ideas for moving forward. And further, to promote use of these stories in a broad range of anti-stigma initiatives such as education and training.
- 4. Identify opportunities to provide training and education on the complexity of substance use issues to health care, social service, police and other professionals. For example, to build on training initiatives underway with emergency room staff to better support patients with substance use issues.
- 5. Develop and promote a range of peer/mentor initiatives to support people struggling with stigma and discrimination related to their substance use. Examples could include, for example, community programs in a central hub/location or integrating peer workers into hospital volunteer programs.
- 6. Advocate for and promote opportunities to expand delivery of primary health care services in community-based services frequently used by people who use alcohol/other drugs. This could include providing primary care clinics in harm reduction programs, drop-ins and shelters.

Conclusion

The Toronto Drug Strategy Implementation Panel undertook this research project to hear from people who use alcohol/other drugs about their experiences with stigma and discrimination to inform the development of recommendations for action. It is clear from the focus groups that people who use alcohol/other drugs in Toronto experience stigma and discrimination in all aspects of their lives with significant impacts on their self-esteem, health and well-being, and access to health and social services, housing, education and employment opportunities.

Action is needed to reduce stigma and discrimination experienced by people with alcohol/other drug issues as well as to support people in coping with the negative impacts it has on their lives. The recommendations in this report provide a concrete step forward to reducing the stigma and discrimination experienced by people who use alcohol/other drugs in Toronto.

Appendix A: Focus Group Discussion Questions

- 1. What types of discrimination or prejudice have you experienced because of your alcohol and other drug use?
- 2. What has the impact of prejudice or discrimination been on you?
- 3. How do you cope with prejudice and discrimination?
- 4. What would help reduce the prejudice and discrimination against people who use alcohol/other drugs?
- 5. What do you think others should know about people who use alcohol/other drugs?

Appendix B: Focus Group Information Survey

Thank you for agreeing to participate in this focus group. The information you provide will be very helpful in the development of Toronto Drug Strategy anti-stigma initiatives. Before the focus group begins, we ask that you complete this short survey. We do not need your name for this survey, and all information will be kept private and confidential. Neither this survey nor the focus group has anything to do with the agency or staff where we are right now. Whether or not you decide to complete the survey or participate in the focus group is completely up to you and this agency is okay with whatever you choose.

Please check the appropriate answer for each question.

1) Do you identify as a	□ Male	
	Female	
	□ Transgender/Transsexual	
2) What is your age?	□ 19 years or under	
	\square 20 years to 24 years	
	\Box 25 years to 29 years	
	\square 30 years to 39 years	
	\square 40 years or more	

3) Do you identify as:

□ White / Caucasian	□ First Nation, Metis, Inuit
🗆 Filipino	🗆 Japanese
Black	🗆 Korean
□ Southeast Asian (e.g., Cambodian, Vietnamese)	Chinese
🗆 West Asian (e.g., Iranian, Afghani)	🗆 Arab
South Asian (e.g., East Indian, Pakistani)	Latin American
□ Other, please specify	

4) What area of the city area of the city do you live in?

□ In the downtown area (former City of Toronto)

□ Outside the downtown area (Please specify area):

□ Scarborough
□ York
□ North York
□ East York
□ Etobicoke

5) Where do you get your money from?

□ No income	□ Ontario Disability Support Program (ODSP)
Ontario Works (OW)	Pension
Employment	□ Other (please specify):

6) In the past month, have you lived in...? (Please check all that apply)

Own apartment/house	□ Jail/prison/correctional facility
□ Rooming/boarding house	□ Shelter/hostel
□ Supportive housing	□ Recovery house/detox
Parent(s)/relatives house/place	Abandoned building/squat
□ Friends place	□ Street
□ Hotel/motel room	□ Other (please specify)

Thank you for taking the time to complete this survey!