ISSUES, IDEAS, AND INDIGNATION:

A Summary of Focus Groups With Women at High Risk for HIV and Other Health-Related Problems

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EXECUTIVE SUMMARY

The Colorado Women's Health Advocacy Coalition is made up of service providers who work with women who are at high risk for and/or highly affected by HIV, other sexually transmitted diseases, and related health and social problems such as substance abuse, mental illness, poverty, homelessness, discrimination, and violence and abuse. First formed in the fall of 2000, the coalition brings together rural and urban providers from various arenas including STD and HIV prevention, women's health, family planning, substance abuse treatment, mental health, homeless advocacy, violence prevention, victim support services, and multiple service organizations that target women and youth. By working together, providers from various arenas can mutually raise each other's capacity and establish the kind of working relationships that will help facilitate women getting more of their needs addressed in ways that are respectful, efficient, and effective.

During 2001, 10 focus groups were held by coalition participants, involving 67 high-risk women in Denver, Boulder, and Alamosa. During these groups, women participants were asked their opinions about the following topics: 1) the major health-related issues that women - especially women in poverty - are facing; 2) the reasons for and impact of substance abuse; 3) physical, sexual, and emotional abuse; 4) HIV risks; 5) HIV prevention programming; and 6) other related service needs.

Several themes emerge from the discussions, which are summarized in this document. One concerns the overwhelming interrelation among substance abuse, mental health problems, violence and abuse, poverty, discrimination, and the risk for getting or spreading HIV. Another theme can be seen in the difficulties that many women confront in trying to get their profound and multiple needs met, as necessary services tend to be inadequate in various ways, as well as institutionally detached from each other. A third theme emerges with a loud reminder that at the heart of so many of the problems discussed is how bad so many women feel about themselves.

The needs that are highlighted begin with a call for services that are more effective, more culturally competent, more respectful, more pervasive, more accessible, and which build on individuals' assets. These needs then continue with a call for those services to be better integrated, either via more multiple service agencies, a sound referral system, or new collaborations.

PARTICIPANT PROFILE

The focus group participants were, almost entirely, women living in poverty. The participants ranged in age from 17 to 56, with a median age of 35 years. Approximately 18 percent of the total sample was African American, seven percent American Indian, 28 percent Latina, and 46 percent white. Less than a third of the women were working. Only 17 percent of those reporting income levels claimed to have incomes over $10,000 a year. Years of education ranged from six to 16 among those for whom such information was recorded (61 percent of the total), with a mean of 11.66 years. Sixty eight percent had finished high school, and, of

those, 22 percent had some education beyond high school. Over three-quarters of the participants reported that they had spent some time incarcerated. Eighteen percent of the entire sample was known to be HIV-infected.

MAJOR HEALTH-RELATED ISSUES

Physical, Sexual, and Emotional Abuse

Childhood abuse appeared to have been very common among these groups of women. Severe physical, sexual, and emotional abuse was discussed, with the perpetrators of such abuse including parents, siblings, extended family, and family friends and acquaintances. The women who came from abusive families talked about the cycle in which women can get caught. Sexual abuse is often not dealt with. The impact of having such a history of childhood abuse ranged from feelings of guilt and low self-esteem to what some described as post-traumatic stress. The women discussed how it can affect a woman's boundaries later in life, often instilling a tendency to have a large number of sex partners (including ones encountered through prostitution) and engaging in a number of "unhealthy" relationships. It is very common that such a history leads to substance abuse problems. Physical abuse and emotional abuse by partners appeared to be quite common, at times involving life-threatening situations. Many of the women mentioned how their men would hold them back by making them feel worthless, ignorant, and unattractive, feeding into the women's propensity for low self-esteem.

Substance Abuse

Much of the discussion on substance abuse highlighted the close interrelationship between substance abuse and women's psychological well-being. The majority of the women had survived very harsh life circumstances stemming from histories of abuse, poverty, and discrimination. The resulting stress, depression, and low levels of self-esteem were cited as the major reasons why women used and abused substances as they temporarily sought to forget their problems, lower stress and anxiety, control their temper, and/or mask depression and other mental health problems. Social environments often contributed to substance abuse, including family dynamics and the character of neighborhoods. The consequences of substance abuse discussed were very profound. Getting through daily life and taking on responsibilities such as seeking and holding jobs, keeping a permanent place to live, maintaining a family, and paying bills were very problematic for those with addictions. Also discussed were the loss of children to Social Services and disrespectful and unfair treatment within the judicial, social service, health care, and other systems as well as by family, friends, and neighbors. Prostitution was seen as a fairly common way for women who are addicts to get by and to support their drug use. For some, it was a way in which they were forced to support their partners' substance use as well.

Discussions of substance abuse treatment programs were mostly unfavorable. The cost, accessibility, and availability of treatment constituted one category of complaints. The waiting period to get into subsidized or free treatment programs proved very problematic for those who felt they needed to act immediately on their decisions to go into treatment. Other

areas of concern included disrespectful treatment, the quality of care offered at many centers and the structure of the treatment programs, especially as it concerned the failure to deal with underlying mental health problems. Problems with the typical duration of treatment programs also were mentioned as women discussed how they needed more time to address addiction-related problems that had been years in the making. The need for after-care was also highly emphasized, as women felt that once they finished a treatment program they needed assistance with getting their lives on track.

Mental Health Concerns

Depression, stress, and feeling overwhelmed were highlighted in all of the groups as factors that commonly weigh on women's ability to cope with life in a positive way as were feelings of loneliness and isolation, fear of abandonment and rejection, grief, post-traumatic stress and anger. A topic that was highly emphasized was that of low self-esteem among women. This stems from a combination of an overall societal devaluation of women and individual histories of disrespectful, discriminating, and abusive treatment by family members, partners, and other people and institutions. Low self-esteem was said to affect addictions, women's ability to support themselves financially, their attempts to get out of abusive situations, their ability to defend their rights in the face of institutional abuse, and their ability to protect themselves from health-related problems such as HIV. Access to quality and affordable mental health care was described as a significant problem by the groups. Subsidized care can prove very difficult to find, especially for those whose problems are caused by factors other than physiological imbalances.

Poverty and Basic Needs

Very low incomes often meant that women were highly dependent on partners, institutions, and, sometimes, illegal activities in order to get by. One major problem cited was the lack of access to affordable, safe, and permanent housing. Finding well-paying jobs was especially difficult for women with substance abuse problems and those who had been in legal trouble. Access to transportation also was cited as problematic for those needing to run errands, access services, and keep appointments.

Health Care Services

Access to quality health care was seen as difficult. Many felt that they were not respected and that they were discriminated against, complaining that they were treated as if they were "stupid", that they were not listened to, and that their conditions were not adequately explained to them by medical providers. The short length of time that providers spent especially was highlighted, as was a lack of consistency of providers and the lack of access to specialists. The long periods of time that they had to wait to access care in public clinics also was a common complaint along with the costs of care, medications, and health insurance.

Women and HIV Risks

Women's risks for getting or spreading HIV and why they have those risks were related to the topics already discussed such as violence, substance abuse, and mental health. Risks included: unsafe sex with multiple partners and/or with high-risk partners; drugs and alcohol affecting judgment; prostitution to support an addiction and/or to meet basic needs; rape; low self-esteem; and lack of empowerment affecting assertiveness, boundaries, and protection. Partner resistance to the use of condoms, denial, impulsiveness, or feeling that HIV is not likely to impact them also affected risk. Lack of empowerment seemed especially problematic for young women who are pursued by older men. Peer pressure and partner pressure to have sex further impact young women with low self-esteem. Exacerbating risk is the way that sex, and especially casual sex, is presented in the media. Lack of availability of sterile syringes and the possible legal consequences of carrying paraphernalia were cited as risks for injectors. Feeling sick from withdrawal was the reason most given for injection-related risk.

The women often cited the lack of comprehensive education about HIV and how to prevent it, especially in the schools, as a barrier to keeping people safe. None of the women in the groups thought that abstinence-based education was giving young people the tools that they needed to make smart choices about sex. The women felt that education about HIV and related illnesses was also lacking for adults, as many discussed how available information was often incomplete and sometimes erroneous.

PROGRAMMING NEEDS AND SUGGESTIONS

When asked to discuss ideas for programs and services that they felt would be most appropriate for women, emphasis was continuously placed on the need for critical services such as those related to substance abuse, mental health, HIV care and prevention, and other health matters to be well-integrated, either by being offered in conjunction with each other or by being soundly linked through a referral system. Suggestions related to integrated programming include: 1) groups for women offering emotional support, education, therapy, enhancement of self-esteem, stress management, coping strategies, empowerment, spiritual support and development of life skills; 2) well-trained, straightforward, compassionate, and culturally competent counselors/group leaders, preferably ones who have successfully confronted major life issues; 3) needle exchange and better pharmacy access to sterile syringes; 4) affordable methadone with fewer restrictions on access, 5) drop-in centers; 6) client advocates; and 7) sound referral systems.

Ideas more specific to HIV prevention also included risk-reduction assistance, HIV-infected group leaders, groups for HIV-infected women, one-on-one intensive interventions, and comprehensive HIV education in schools starting in elementary school.

Ideas specific to substance abuse treatment included the need for more dual-diagnosis (substance abuse and mental health) treatment, more longer term, inpatient care, more subsidized treatment, aftercare, and treatment on demand.

Ideas specific to mental health treatment included the need for more subsidized care and help dealing with the consequences of abuse. Also suggested were better access to medications for those with biologically-based problems, more dual-diagnosis providers to serve people who also have substance abuse problems, and counselors with the proper expertise to deal with the tough life issues many high-risk women face.

Ideas for abuse-related programming include more places to which women can retreat, even if they are "high," as well as stricter investigation of abuse cases, stricter prosecution, and more extensive punishment of perpetrators. This seemed to be especially needed in the case of childhood sexual and physical abuse.

Ideas for health care services and services related to basic needs are implied in the critiques listed in the appropriate sections above.

CONCLUSION

A principle purpose of this summary document is to bring to light the depth and complexity of the life issues confronted by the participants in these 10 focus groups and the many women living under similar life circumstances. The results of these groups most clearly emphasize the fact that substance abuse, mental health problems, violence and abuse, poverty, discrimination, and the risk for getting or spreading HIV are so extensively interconnected, and our mostly disconnected service systems are poorly equipped to deal with these multiple needs as effectively as they could. The need for the integration of services is currently being discussed at many levels, including among federal agencies such as the Substance Abuse and Mental Health Services Administration, the Centers for Disease Control and Prevention, and the National Association of State and Territorial AIDS Directors who met on this subject in February 2002. The coalition expects that future guidance from federal partners will contribute to Colorado's efforts to develop new collaborations among various agencies.

FOCUS GROUP SUMMARY

INTRODUCTION

The Colorado Women's Health Advocacy Coalition is made up of service providers who work with women who are at high risk for and/or highly affected by HIV, sexually transmitted diseases (STDs), and related health and social problems such as substance abuse, mental illness, poverty, homelessness, discrimination, and violence and abuse.[1] First formed in the fall of 2000, the coalition brings together rural and urban providers from various arenas including STD and HIV prevention, women's health, family planning, substance abuse treatment, mental health, homeless advocacy, violence prevention, victim support services, and multiple service organizations which target women and youth. Given that the issues that many women face are highly interrelated, especially those faced by women of color and women who are living in poverty, the participants in the coalition recognize that it is not effective to provide HIV and STD prevention or related services in a vacuum. By working together, providers from various arenas can mutually raise each other's capacity and establish the kind of working relationships that will help women get more of their needs addressed in ways that are respectful, efficient, and effective.

Near the beginning of 2001, coalition participants agreed upon some initial goals. These included: 1) to gather information from at-risk women about their issues, needs, assets, and ideas that can be used to guide the development of programming; 2) to identify current gaps in services; 3) to increase the capacity of service providers to offer appropriate and effective services that are respectful, culturally competent, accessible, and client-centered; 4) to develop appropriate interagency relationships to ensure a sound referral system; 5) to identify and disseminate relevant research; and 6) to influence the way relevant service systems function and interact.

The group decided that effectively addressing Goals 2-6 above was highly dependent upon obtaining the information as described in the first goal and combining it with other relevant information (published and unpublished) to form the basis of further planning and coordination. Therefore, a series of focus groups were planned for the spring and summer of 2001 as part of meeting this goal. Between April and September of that year, a total of 10 such groups were held, involving approximately 67 women. These groups took place at the following locations in Denver: 1) The Gathering Place; 2) Urban Peak; 3) The Empowerment Program (two groups, one with HIV-infected women); 4) Northeast Women's Center; and 5) Denver Public Health (also a group with HIV-infected women). Four groups were held at locations outside of Denver. These included: 1) Willow House in Alamosa; 2) Alamosa Mental Health Center; 3) Monte Vista Mental Health Center; and 4) the Boulder County Jail.

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[1] In this document, the terms "at-risk" and "high-risk" refer to vulnerability to multiple, interrelated issues, including HIV, STDs, substance abuse, mental illness, poverty, homelessness, discrimination, and violence and abuse.

During these groups, women participants were asked their opinions about the following topics: 1) the major health-related issues that women, especially women in poverty, are facing; 2) the reasons for and impact of substance abuse; 3) physical, sexual, and emotional abuse; 4) HIV risks; 5) HIV prevention programming; and 6) other related service needs.

This qualitative study constitutes a critical piece of formative evaluation drawn directly from high-risk women, which identifies their issues and assets, as well as gaps in and barriers to their access to the services necessary to meet a broad range of health-related needs. The experiences and opinions described here are their own. This summary report reflects and will serve to inform the meeting of the two overarching goals designated in the *Healthy People 2010* health objectives, which include: 1) increasing quality and years of healthy life; and 2) eliminating health disparities. Further, the report addresses several of the focus areas in the *Healthy People 2010* document, including access to quality health services, family planning, HIV, injury and violence prevention, mental health and mental disorders, sexually transmitted diseases, and substance abuse.

This report also reflects the following aspects of the Colorado Department of Public Health and Environment's four year strategic plan, "Challenges and Opportunities for a New Century," as it addresses three of its four designated "critical investment areas:" prevention, disparities, and protection. During the focus groups described, women were encouraged to identify healthy lifestyles and ways to avoid risk factors that contribute to premature death and disability rates. They also were able to discuss the barriers they face in adopting such lifestyles and avoiding risk, challenging the public health system to address these barriers. The report will further the effort to eliminate health disparities as it relays the voices of African American, Latina, and Native American women, as well as women facing poverty, incarceration, violent relationships, homelessness, addictions, and mental illness. It more specifically addresses the disproportionately high rate of HIV among women living in poverty, especially African American women. Finally, in the area of protection, the report presents an overview of the barriers these women face in accessing health care and offers suggestions for improving such access. Core strategies outlined in the Colorado Department of Public Health and Environment's strategic plan, which also will be advanced by this report, include prevention and education, placing a particular emphasis on the need for collaborative efforts among agencies that are critical to effectively meeting the needs of some of Colorado's most vulnerable residents.

Several themes emerge from the discussions that are summarized in this document. One concerns the overwhelming interrelation among substance abuse, mental health problems, violence and abuse, poverty, discrimination, and the risk for getting or spreading HIV. What is heard from the participants is, therefore, the futility of trying to deal with each of these separately in ways that are truly effective, yet the existing service systems are structurally very disconnected. Another theme can be seen in the difficulties that these women confront in trying to get their profound and multiple needs met, as necessary services tend to be inadequate in various ways as well as institutionally detached from each other. A third theme arises with a loud reminder that at the heart of so many of the problems discussed is how bad so many women feel about themselves. As women make efforts to try to deal with these

problems and access needed services, they continuously face additional difficulties that often validate and/or exacerbate their already low self-esteem.

As the Colorado Women's Health Advocacy Coalition and others look at the results of the focus groups, it may be easy to get overwhelmed and bogged down in trying to decide where to start in addressing these issues given the resources available. The needs that are highlighted begin with a call for services that are more effective, more culturally competent, more respectful, more pervasive, more accessible, and which build on individuals' assets. These needs then continue with a call for those services to be better integrated, either via more multiple service agencies, a sound referral system, or new collaborations. Obviously the coalition or any other group of providers cannot take on every issue or substantially influence system change overnight. It can, however, begin to make in-roads with the individual agencies, challenging them to rethink approaches that may not be the most appropriate. The coalition can identify areas where it can raise awareness among service providers and raise capacity to more effectively meet women's needs. It also can begin to look at the possibilities for better integrating services and begin to look at ways to develop new resources to start filling some of the identified gaps in service. If service providers are to make a difference in the lives of high-risk women, these testimonies cannot be ignored.

Overall, this summary is meant to shed light on key issues that many women in poverty face. Its main purpose is to provide information to assist in the development of more comprehensive, effective, and culturally competent programming for high-risk women with multiple needs. It should be noted that the women in the focus groups do not necessarily constitute a representative sample of women who live in poverty; nevertheless, it is the coalition members' professional opinion that the issues they discussed are pervasive. This report is not meant to be critical of any particular agencies, but, instead, to identify opportunities for improving and expanding services available to women and to form the basis for further research.

PARTICIPANT PROFILE

The focus group participants consisted almost entirely of women living in poverty. Most of them could be considered to be living in situations where they are at high risk for getting or spreading HIV and at high risk for other related health and social problems as well. The participants were recruited through coalition members based on these members extensive experience and knowledge of the types of women who tend to be at highest risk. Seven of the focus groups included clients at agencies represented on the coalition. The groups held at Urban Peak, Northeast Women's Center, and Willow House were made up of women accessing services at those agencies and were recruited by agency staff just prior to the holding of the groups. Demographic information on the women who participated in these groups is incomplete, though some information was collected from 62 of the 67 women. In three of the groups, only information on the number of participants and ethnicity was collected. In seven of the groups, more complete information was collected on factors such as age, income and education levels, experience with the correctional system, and HIV testing history.

The participants ranged in age from 17 to 56, with a mean and median age of around 33 and 35 years respectively. Approximately 18 percent of the total sample was African American, seven percent American Indian, 28 percent Latina, and 46 percent white. One person identified as being of mixed descent. Among the six groups that were held in Denver, the ethnic breakdown was 28 percent African American, eight percent American Indian, 15 percent Latina, and 46 percent White. Less than a third of the women were working. Only 17 percent of those reporting income level claimed to have incomes over $10,000 a year. That percentage would be significantly lower if information had been available from the three other sites, given that most of the participants at those sites also were unemployed or only marginally employed. Years of education ranged from six to 16 among those for whom such information was recorded (61 percent of the total), with a mean of 11.66 years. Sixty-eight percent had finished high school. Of those, 22 percent had some education beyond high school, and five percent had finished four years of college. Over three-quarters of the participants reported that they had spent some time incarcerated. Of the 63 percent who reported on HIV testing, 79 percent said they had been tested. Eighteen percent of the entire sample was known to be HIV-infected.

MAJOR HEALTH-RELATED ISSUES

The principal issues that surfaced for women during these discussions are presented here as part of five major categories. These include violence and abuse, substance abuse, mental health, basic needs, and health and health care services. Each was discussed in some detail, though the details and emphases varied between the groups. Direct quotes from the focus group participants are included in italics in the text below.

Physical, Sexual, and Emotional Abuse

Childhood abuse appeared to have been very common among these groups of women, though some groups were more inclined to talk about the subject in depth than others. This could be due in part to differences in the way the subject was broached by the facilitators. Severe physical, sexual, and emotional abuse was discussed, with the perpetrators of such abuse including parents, siblings, extended family, and family friends and acquaintances. The women who came from abusive families talked about the cycle in which women can easily get caught, seeing domestic violence as somehow "normal" to the point where they tend to seek out partners who have a tendency toward violence and/or they become violent themselves. One young woman with a history of sometimes life-threatening abuse talked about how it is hardest to deal with it when it is parents inflicting the violence.

> *"There's this person that's supposed to love you, and when you're little, you don't know if they're going to hug you or push you down the stairs. You get so confused….Am I supposed to love them or not? But then you end up loving them."*

> *"I think a lot of the problem is not being loved and not knowing what love is all about. In some families that's true. I came from an abusive family and that was love to them. Instead of hugs there was a lot of beatings. When I had kids, I had a hard time showing love to them. I didn't abuse them, but in a sense I did, 'cause I didn't hold them and hug them and talk to them as much as I should have. It just passes on."*

> *"If you're used to abuse as a child, you get comfortable with it. You look for it in men or are kind of attracted to that kind of man."*

Several women talked about young girls not being believed when they try to tell other family members about sexual abuse. Some are told not to tell, or they are told that the abuse was their own fault. The women felt that even Social Services or the judicial system were inclined toward not protecting the children and would commonly "reunite" perpetrators and victims from the same family.

> *"You don't tell because your parents don't want to hear it. You're supposed to live with it."*

The impact of having a history of childhood abuse was acknowledged to be quite profound. It ranged from feelings of guilt and low self-esteem to what some described as post-traumatic stress. The women discussed how it can affect a woman's boundaries later in life, either making them frigid, callous, and inclined to shut people out or instilling a tendency to have a large number of sex partners (including ones encountered through prostitution) and engaging in a number of "unhealthy" relationships. It was very common in these groups that such a history eventually led to substance abuse problems.

> *"You end up not feeling. Sex is just an act that gets you change in your pocket."*

> *"I was sexually abused and now I'm a very promiscuous person, very sexual. It feels good at the time, but when you're not getting a call back, or they're ignoring you, or they're all over some other female, you're like, 'Well, damn! Maybe I wasn't special.' And then you've got these self-esteem issues, which bring that desire to have that good feeling again. So you get in this cycle."*

Serious abuse by husbands and other primary partners received a significant amount of attention in all of the focus groups. Physical abuse appeared to be quite common, and some women mentioned having experienced circumstances that were truly life-threatening. In some cases, the physical abuse extended into situations such as men forcing women to prostitute to help support their own drug habits and, in one case, to provide entertainment for friends. Three of the women who were HIV-infected had acquired those infections from husbands, two of whom never disclosed their HIV status throughout several years of marriage.

"The use and having my problem with the car accident and the abuse…, it's all messed up my brain bad. Now I have to take more seizure medications. I'm talkin' with the devil here lately with all the medication they're putting me on to keep me from having seizures."

Emotional abuse on the part of husbands and other primary partners also was a topic of extensive discussion. Some men were said to be very controlling, limiting the amount of time women spent with other people, especially friends and family, and expressing suspicion and jealousy even when the women went to run errands. Some women discussed how their men controlled them by trying to keep them using drugs. Many of the women mentioned how their men would hold them back by making them feel worthless, ignorant, and unattractive, feeding into the women's propensity for low self-esteem. Such feelings coupled with financial dependency kept some women in these relationships for long periods of time. Two of the HIV positive women talked about how their husbands would try to control them by threatening to disclose their HIV status.

"They don't want to see you get ahead. They want to see you down because they're down."

"My using drugs and my husband being abusive, it was a whole power trip with him where he could keep me where he wanted me. I had got clean and he felt powerless. He became irate and I had to put him in jail. You ain't hittin' me no more."

Many of the women in these focus groups have been victims of rape. They talked about the fear that they continue to live with in their homes, on the streets, and even in places such as shelters and detox centers. Homeless women spoke of having to stay awake all night and then finding a place to sleep during the day in order to stay vigilant, and they spoke of feeling defenseless when approached by men on the street. The women in Denver felt that there were only a limited number of shelters that they could access when they needed them, and they were often full. One woman remarked how when a woman needs someplace to retreat, sitting at a pay phone and trying numbers listed in the phone book until she finds a place that can take her is not a viable option. Such services for women outside of Denver are even more limited.

"Rape is pretty common. I was 13. You just try to put it out of your mind. I've done every kind of drug, heroin, crack. The men that I pick tend to be assholes."

"I have sex, not because it's what I really want to do. I've been raped, sodomized, whatever. If I'm having sex, you better know that someone's paying for it."

Other types of abuse that were discussed by the women included abuse by the police, social service agencies, and health care providers. Sexual harassment and sexual discrimination also were added to the category.

"It makes things worse when you go to the police. You get threatened worse, and usually you're the one that ends up going to jail."

"I think sexual harassment is a form of violence. That happens all the time…uninvited comments or touching, or giving someone a job that you're more qualified for because they're better looking or because they're a man. I've had sexual harassment all my life."

Substance Abuse

A subject that received much of the attention in each of the focus groups was that of substance use and abuse. It was first highlighted as a major issue affecting women's health. The subject then moved to why some women tend to get involved in substance use and often end up with addiction-related problems. Most of the discussion that followed in all of the groups highlighted the close interrelationship between substance abuse and women's psychological well-being.

The majority of the women participating in these groups had survived very harsh life circumstances stemming from histories of abuse, poverty, and discrimination. For some of the women these circumstances included having to deal with HIV infection, biologically and environmentally influenced mental disorders, and loss of children and/or other loved ones. The resulting stress, depression, and low levels of self-esteem were cited as the major reasons why women used and abused substances as they temporarily sought to forget their problems, lower stress and anxiety, control their temper, and/or mask depression and other mental health problems.

"The day I found out I had HIV I started doing heroin."

"What got me using is that I had a real sick little girl. She lived to be two-and-a-half. They told me she would live to be five, but she died. It was really hard on me. I turned into a heroin addict, and that's how I ended up with HIV through needles. I tried to get into a methadone clinic, but you had to pay and I didn't have no money to pay, so I just kept using."

Many women highlighted the role of the social environment in contributing to substance abuse. Some talked about drugs and alcohol use being an integral part of a relationship with a partner. Another emphasis was on the impact of substance abuse within families and how such abuse can seem almost "normal" and become a pattern from an early age.

"I can't blame them. How can you blame someone who's sick? Or how can I blame myself when I'm sick? It's a disease and the people that raised me were suffering from the same disease."

"I was a crack baby, and I've done drugs. I wasn't dependent on drugs, but you think my mom cares while she shoots up and has me watch her? Drugs complete a feeling. You're saying it's wrong, but when you have nothing, you say, 'What do I do? My mom won't talk to me. I'm happy.' Yeah, when I go to sleep and wake up the problem is still there, but for that minute, I'm happy."

Neighborhoods also were blamed for influencing substance abuse, especially in their role in impeding a person's efforts to "get clean." In areas where the use of drugs is very common and the availability is extensive, the pressures to begin using and keep using drugs can be very high.

"There are drugs all over the neighborhood and people always trying to sell you some. If you're stressed out already you go for it."

Other rationales for why women tend to get involved in substance use were mentioned but were not highly emphasized in any of the discussions. The groups in the San Luis Valley discussed how there was often not much for young people to do but do drugs and have sex. A few of the women mentioned that people often use drugs and alcohol because they think it is fun. Peer pressure, the desire to lose weight, and the need to stay awake in order to take care of all of the things one needed to get done also were brought up. Another point considered the role of prescription drugs in leading to some people's addictions.

"Think about the number of things we're supposed to do everyday. You go to work and then you come home and have all these other things to do for the family, and then it's time to go to bed. And then you don't sleep good. And then it starts all over again."

The consequences of substance abuse discussed by the women in the focus groups were very profound. Many of the women considered themselves to be addicts, some in recovery and others actively using. Getting through daily life and taking on responsibilities such as seeking and holding jobs, keeping a permanent place to live, maintaining a family, and paying bills was very problematic for those with addictions. A highly discussed topic concerned the loss of children to Social Services due to substance abuse and poverty. It was mentioned that substance abusers who have good incomes rarely end up losing their children since they tend to be looked at more favorably by the system, and they can afford legal counsel. Overall, disrespectful and unfair treatment within the judicial, social service, health care, and other systems was extensively highlighted as well as similar treatment from family, friends, and neighbors. The subject of discrimination against women who use drugs and alcohol was discussed in almost all of the groups.

Prostitution was mentioned as a fairly common way for women who are addicts to get by and to support their drug use. For some it was a way in which they were forced to support their partners' substance use as well.

"My husband…something he would do to keep the high going, he'd send me out on the street to have sex. If I didn't, I'd get smacked or verbally abused. Then he would call me down for doing it."

Many of the women talked about specific health problems, which are often caused or exacerbated by the abuse of drugs and alcohol. Being "high" was related to a tendency toward having unsafe sex, making women vulnerable to sexually transmitted diseases, including HIV. Hepatitis C stemming from the use of injectable drugs was mentioned as well as the liver damage caused by both the hepatitis and a high level of alcohol consumption. Accidents and injuries also appeared common. A final consequence of substance abuse cited by the group stemmed from its role in exacerbating domestic violence situations.

The participants in the focus groups with substance abuse problems discussed their experiences with treatment programs, and, in most cases, in ways that were very unfavorable. The cost, accessibility, and availability of treatment constituted one category of complaints. Given the very low incomes of most of the women participating, paying for expensive treatment or having insurance cover the costs was not an option. The waiting period to get into subsidized or free treatment programs proved very problematic for those who felt they needed to act immediately on their decisions to go into treatment if they were to stop using. One woman discussed how she had tried to get into a methadone program but could not afford it. She felt that this contributed to her later becoming HIV-infected due to using injection "works" with other users. Once she became infected, the costs of methadone could be paid for through public monies.

"Treatment and I don't get along. It don't help. I just walk out of there and do the same thing."

"A lot of times there are waiting lists and that doesn't help. I'm not going to stay sick, and I need help right now. I can't wait two weeks or one week. I gotta go now. I've been to the point where I've gone to jail because I'm in a situation where I need to get help, and I don't care how I'm gonna get it. So I'm gonna go commit a crime because I need something so I can get better. I can't live like this."

"Treatment centers all want money up front. I can't afford that, and I need help. I get so far out there that there's nowhere for me to go."

Other areas of concern about substance abuse treatment stemmed from the quality of care offered at many centers and the structure of the treatment programs. Many of the women felt that they had been treated disrespectfully by clinic staff and counselors and that some of the counselors were underqualified. It is not uncommon for counselors to be people in recovery, and, depending on their training and perspective, they may take a very narrow view of the proper road to recovery. The issue was frequently raised about how treatment often just deals with the substance use of a person and techniques for stopping that use. For those who began abusing substances because of mental health problems often stemming from histories of

serious physical, sexual, or emotional abuse, the need to deal with those underlying issues can be great. Yet many substance abuse counselors are not trained to deal with such issues.

> *"A lot of times with the mental part of it, a lot of people go misdiagnosed. They think that it's an addiction problem and it's really a mental problem. You've got all these things going on, and it's being covered up by the substance use. Then they send you back out there on the streets and you're just as messed up as when you went there, because you never had the real problem dealt with."*

Problems with the typical duration of treatment programs also were mentioned as women discussed how they needed more time to address addiction-related problems that had been years in the making. The need for aftercare also was highly emphasized, as women felt that once they finished a treatment program they needed assistance with getting their lives on track (e.g., looking for work, paying bills, etc.) as well as needing a counselor to follow up with them to see how well they are getting by. Needs for more affordable in-patient programs and detox facilities that were safer for women also were discussed. Those who expressed having more successful experiences with treatment were women who had been in inpatient care, had their mental health concerns addressed, had assistance with life-skills, and felt that they had highly qualified counselors who could deal effectively with their issues.

> *"There's no aftercare. And you just can't leave me on the street and expect me to stay clean without any kind of support. They're fooled when they think 28 days, 14 days is enough treatment. I've been drugging since I was 12…for 14 years. So how am I going to go for 14 days and then live my life right? It takes years before you can finally live your life in recovery fully."*

Mental Health Concerns

Many of the mental health problems discussed by the women in these groups have already been mentioned in the two previous sections given that they are so highly inter-related with histories of violence and substance abuse. Depression, stress, and feeling overwhelmed were highlighted in all of the groups as factors that commonly weigh on women's abilities to cope with life in a positive way. Feelings of loneliness and isolation played a role as well as fear of abandonment and rejection. Some women spoke of loss or grief from losing loved ones, especially children, either to death or (in the case of children) to Social Services. Grief also was an emotion expressed by the women who were HIV-infected. Clinical depression and bipolar disorder were mentioned as factors that some had to confront, as well as post-traumatic stress and anger. Several women discussed spiritual breakdown as well, and eating and sleep disorders were talked about as common symptoms of the mental health problems women face.

> *"Whether depression causes alcoholism or alcoholism created depression, it's a catch-22. They feed off each other"*

A topic that was highly emphasized in all of the groups and throughout the discussions was that of low self-esteem among women. This stems from a combination of an overall societal devaluation of women and individual histories of disrespectful, discriminating, and abusive treatment by family members, partners, and other people and institutions. Low self-esteem was cited as a factor in many of the daily battles these women face, including addictions, their ability to support themselves financially, their attempts to get out of abusive situations, their ability to defend their rights in the face of institutional abuse, and their inclinations to protect themselves in the face of health-related problems such as HIV.

> *"That's where the self-esteem comes in on the women's part when they go for the abusive men. Women with low self-esteem end up being in more violent relationships. A person with high self-esteem isn't going to put up with it. They'll get out."*

> *"Most women when they're in abusive relationships they're getting a validation of what they think of themselves anyway. They have low self-esteem and they will migrate to partners who validate that."*

> *"Self-respect is hard to come by these days."*

Access to quality and affordable mental health care was described as a significant problem by the groups. Subsidized care can prove very difficult to find, especially for those whose problems are caused by something other than physiological imbalances. Those with such imbalances discussed difficulties in maintaining a steady source of the necessary medication given that few had health insurance or consistent providers who were following their cases. Some felt that many of the counselors that they had seen were not equipped to deal with the depth of life problems they faced and therefore were not able to be very helpful.

Poverty and Basic Needs

As mentioned above, the vast majority of the women participating in these focus groups had very low incomes, making them highly dependent on partners, institutions, and, sometimes, illegal activities, in order to get by. One problem that was discussed by all of the groups in Denver and the one in Boulder concerned the lack of access to affordable, safe, and permanent housing. In fact, many of the women in the urban groups were homeless. Subsidized housing is in short supply, and qualifying can be very problematic, especially for women who do not have children or whose children are not living with them. Though some of the women had permanent residences, others accessed temporary housing and shelter through Empowerment, Urban Peak, The Gathering Place, and various homeless shelters, though the availability of the latter seemed especially limited for women. Some women admitted to prostituting in order to pay for a motel room, while others said they occasionally traded sex for a place to stay. Some, at times, lived on the street. Those with substance abuse problems expressed special concerns about accessing housing in neighborhoods where drugs were prevalent.

"It's not safe out on the street, and a man will approach a woman in a minute. And no matter how tough you are, there's nothing you can do."

"Housing is a big thing if you don't have kids. Being single, I've been trying to get housing for eight to nine months, and I can't get no housing."

"The cost of housing is ridiculous."

Since many of the women had substance abuse problems, minimal education, and/or had spent time in jail or prison, finding well-paying jobs was difficult. Some women expressed that once employers see that a person has a record, she does not stand a chance of getting hired. One claimed to have lost a job she had held for many years due to some misdemeanor charges. Some participants claimed to not have the skills or education that they needed to get well-paying and/or steady jobs. The majority of the sample was currently unemployed, and nine of the women who were employed had incomes of less that $10,000 a year. This meant that providing for oneself and for one's children was very problematic.

"There ain't no jobs when you're in trouble. They run a check on you, and you're out the door. If they see you've been convicted of something they can't hire you."

A topic that arose frequently in the discussions had to do with access to transportation. Many of the women in Denver relied on the buses to get around and relied, in some cases, on agencies for tokens and passes. Problems of relying on buses to run errands, access services, and keep appointments were mentioned by several of the women, but seemed most difficult for those with HIV. For those living in the San Luis Valley, public transportation is not available at all.

"Sometimes it's just simple stuff like how am I gonna get there?"

Other basic needs that some of the women in the groups felt they had trouble accessing included food, baby formula, clothes, and diapers. Lack of affordable and quality day care also was mentioned. Some expressed a need for "healthy" forms of entertainment or things to help them feel better about themselves like a trip to a hair salon. A few women pointed out that there are some available services out there for women, but many did not know about them.

Health Care Services

The final set of issues that arose as major concerns for the women in the focus groups was related to health and health care. Some of the health problems that were mentioned included HIV, other STDs, hepatitis C, accidents and injuries, and teen pregnancy. One of the HIV-infected participants only recently was accessing care and was very upset and frightened to find out that her viral load was over a million. Among those who were on HIV medications there was significant discussion of the side effects and their impact. Though some were doing

quite well, others felt sick often. One woman even questioned if the medications were worth the trouble.

> *"You can't eat and if you do eat you'll get sick. I didn't feel like I had HIV until I started my medication."*

One issue that stood out in this part of the discussions concerned the way that women often get treated when they try to access health care. Many felt that they were not respected and that they were discriminated against, complaining that they were treated as if they were "stupid", that they were not listened to, and that their conditions were not adequately explained to them by the providers. The short length of time that providers spend especially was highlighted. Provider competence in some cases was questioned as well as lack of consistency of providers and the lack of access to specialists. The long periods of time that they had to wait to access care in public clinics also was a common topic. The costs of care, medications, and health insurance were seen as definite deterrents to receiving quality care, with many implying that people with good incomes did not face these same difficulties.

> *"A lot of times we get judged, not only by parents and families, but by doctors and people who are supposed to be helping you."*

> *"If you're a woman they look at you like you're crazy, even if your symptoms seem severe to you. They treat you like you're stupid."*

> *"It's scary to stand up to a doctor."*

Other problems mentioned included a lack of follow-up by providers as some felt it would be beneficial for someone to check back with them and discuss how things were going. A lack of health-related education was another topic, some citing the need to understand health problems better as well as ways to prevent them. A final issue that was expressed was an overall fear of accessing health care or screenings. This is due either to a desire to avoid the kind of treatment that they or others they know have received in the past, or to a fear of possibly finding out that they have a serious medical condition.

WOMEN AND HIV RISKS

Sexual Risks

When asked what women's risks were for getting or spreading HIV and why they think they have those risks, many of the issues that arose were related to the topics already discussed such as violence, substance abuse, and mental health. In talking about sexual risks, unsafe sex with multiple partners and/or with high-risk partners surfaced as the most common type of risk. Some of the most discussed reasons for such risks included drugs and alcohol affecting women's judgment, the use of prostitution to support an addiction and/or to meet basic needs, rape, low self-esteem, and lack of empowerment affecting assertiveness, boundaries, and protection.

"If you're homeless, people exploit you. They give you drugs and/or offer you a place to stay and something to eat, and then tell you the conditions. If you're desperate, you'll do anything, especially for your kids."

Partner resistance to the use of condoms was commonly discussed, as the women claimed that it was often very difficult to get men to use them. Three of the women who were HIV-infected talked about how their partners were HIV-negative but refused to use condoms, denying their risk in spite of knowing about the women's HIV status. One woman discussed how when she disclosed her status to casual partners, they would not believe her because she did not look sick. Two of the women talked about husbands who for years knowingly exposed them to HIV through unsafe sex without disclosing their positive status.

"Some people don't want to wear condoms and the women need the drugs or alcohol so bad they take a chance."

Women's denial of risk was discussed as well, as they judge partners by how they look, get caught up in the "heat of the moment", or do not feel that HIV is something that is likely to affect them. One HIV positive woman said that she knew her husband had a history of injection drug use, but truly did not think he could have HIV, because it was a disease for gay men. She said that in small towns, the truth about risk is still not widely known. Denial also was discussed in terms of high-risk women who think they are probably HIV-infected but do not want to know, so they do not get tested. One woman living with HIV expressed frustration in not being able to convince her sister, who tended to have multiple partners, to protect herself. Though some women in the group talked about feeling empowered enough to insist on condom use and felt other women should do the same, others seemed to assume that the ultimate decision about using protection was that of men. Some mentioned how bringing up condom use can often cause partners to get angry and accuse the women of being untrustworthy. Others mentioned that if you were using drugs with someone, precautions got put aside due to necessity.

"You've just smoked a bowl of dope, and, by that time, it's as good as done".

"If you bring up condoms they always end up turning it around on you. Discussing condoms can lead to more negative discussions than positive ones. It can lead to jealousy."

"You have that love and think he's going to be there for you, and you don't think about protection. You think that whatever happens to you he's going to be there."

Lack of empowerment seemed especially problematic for young women who are pursued by older men. Whether they are flattered by the attention, proud to flaunt their older partners in front of their friends, or looking for father figures, control over these relationships was discussed as being in the hands of the men. Women in the groups also talked about peer pressure and partner pressure to have sex and how that affects young women with low self-

esteem who feel a strong need to be popular or who think that they need a man's attention to feel better about themselves. Exacerbating this was the way that sex, and especially casual sex, was presented in the media as something very normal, widespread, and expected, even among young people.

> *"If there's not anyone to care for you and your dad's not there to care for you and this older guy is there saying he's going to care for you, you feel like you owe him sex, and he presses upon you that you owe him. This older man doesn't really intend to take care of you and be there for you."*
>
> *"It's like a father substitute. If you see a 13-year-old girl and a 24-year-old guy, what is he there for? He's supporting her by even being there and showing her love. And she's not getting it at home. It used to be kids would turn to gangs for that. Now girls are turning to older guys for that."*

Injection-Related Risks

Injection drug use and risks for HIV and other diseases also were discussed in the groups, however not to the same extent as sex-related risks. The availability of sterile syringes and the possible legal consequences of carrying paraphernalia was a common topic. Some felt they had no problems accessing syringes through pharmacies, and one woman who is diabetic mentioned that she often gave her syringes away to drug users that she knew because she felt sorry for them and wanted them to be safe. Others talked about themselves and others "sharing" syringes and other "works." Some use drugs with people they know, assuming that they do not have any diseases. The reason most given was that when people are "sick" from withdrawal, they do not care about anything else and will do anything to get "high." Some of the women told stories about people that they know who would desperately use any "works" that they could find no matter what the condition. Many felt that Colorado needed needle exchange as well as more pharmacy access to syringes, though one woman stressed how the needle exchange would have to be practically next door if people were going to use it. If it were safer to carry syringes around, many thought people would be more inclined to use new syringes.

> *"It's because you get so sick that you have to hurry up and get high. You're not thinking about HIV. You're thinking about getting well."*
>
> *"When I'm at that point, I don't want to be bothered. I don't want to hear nothing. I don't want to worry about making it clean. I don't bathe, shower, or brush my teeth, so how can I care about getting a clean needle."*

Methadone treatment as an option to shooting heroin was only specifically talked about in one of the groups. Both the cost of treatment and the way that program participants are dealt with at the clinics were at issue. One woman felt that if she had been able to get on methadone when she first tried, she would never have become HIV-infected. It was the cost that kept her out of treatment, though counselors often express that if the participants are able to find the money to buy drugs, they should be able to pay for their methadone. The woman also

expressed how the restrictions and requirements placed on her by the clinic were often degrading and hard to accommodate. Additionally, she claimed that she has had counselors from outside of the methadone clinic threaten to compromise her access to methadone if she did not comply with certain restrictions that they had imposed.

Other Issues Related to HIV Risk

Women in the focus groups felt that it was important to discuss some of the social and cultural factors related to HIV risk as well, some of which have already been mentioned or alluded to above. These would include the sexism that feeds into unequal power for women in relationships and certain types of discrimination that affect their incomes and lack of access to certain services. Denial also was a common theme among all of the groups, as the women discussed how many people just do not want to acknowledge their risks for HIV, which stem from their own behaviors or those of their partners. Certain stereotypes about who is at risk for HIV (e.g., gay men) help to feed the denial as well, influencing a tendency for heterosexuals to not see HIV as something that affects them. For those who do see themselves at high-risk, such as injection drug users, prostitutes, and others with multiple high-risk partners, a certain fatalism can influence their behaviors. In other words, there are people that assume they probably already have HIV, or they are bound to get it given their lifestyle. Therefore efforts to protect themselves may seem futile.

> *"I thought that you could only get it from being gay. People need to be more educated about it. I think more education would have helped me not get it 'cause I knew he used to shoot up. I didn't really know it was connected with the tracks."*

Though most of the women participating in the focus groups had been tested for HIV, they were of the opinion that there were many high-risk people who did not know their status, some because they were afraid to test and some because they had not really thought about it. Therefore they thought it was a common occurrence that HIV-infected people were unknowingly exposing others to the disease. All of the groups discussed a lack of comprehensive education about HIV and how to prevent it, especially in the schools. None of the women in the groups believed that abstinence-based education was giving young people the tools that they needed to make smart choices about sex. They expressed how unrealistic it was to only talk about abstinence to adolescents, many of whom already were sexually active. The women felt that education about HIV and related illnesses also was lacking for adults, as many discussed how available information was often incomplete and sometimes erroneous.

> *"A lot of people think that when you have HIV you look a certain way… real skinny, like when you're full blown and sick. I've had men tell me when I tell them to put on a rubber and they'll say, 'What for? I ain't got nothin', and I know you don't got nothin'. And I'm like, 'You know I don't? What if I told you I had HIV?' And they'd say they know that ain't true. And you know I ain't gonna say, 'Yes it is.'"*

> *"Abstinence education isn't going to help them. They're already doing it."*

GROUP SIMILARITIES AND DIFFERENCES

Although many themes and topics emerged as concerns for all of the various focus groups such as violence, substance abuse, depression, and low self-esteem, there were some differences in the topics that were mentioned and certainly differences in what was emphasized in each group. Some of the more prevalent differences were related to the average age of the group members, geographic locations, and HIV serostatus.

Youth

Only one of the focus groups was entirely made up of participants who were under the age of 21. The age range of the group conducted at a youth homeless shelter in Denver, Urban Peak, was between 17 and 20. Because many of these young women had recently left home or had run away from foster care because of physical, sexual, and emotional abuse on the part of family members and friends, such abuse formed the focal point of much of their discussion. They emphasized how growing up in an environment of violence made violence almost seem normal as they saw the cycle continue with members of different generations taking on the roles as victims and/or perpetrators. Such violence usually was coupled with exposure to severe substance abuse problems as well on the part of parents and other family members. In such an environment where so many emotional - and sometimes other - needs go unfulfilled, young women often tend to seek out intimacy and surrogate family in their relationships with men, especially older men, though the results can tend to be equally disappointing. A fairly recent history of rape also was very common in this group of young women.

> *"You can get out of a domestic violence situation with a guy or girl, but if it's your parents, they're always there. You can't get away from the emotional abuse and sometimes from the physical abuse. Even when they die, they're still in your head because they're your parents."*
>
> *"My mom used to be a crack head and now she's all about crystal. She was abused by my grandfather her entire life, and she got caught in that cycle. She gets abused by her boyfriend, and so she smokes more crystal and gets bitchy and then gets abused again and smokes more."*
>
> *"My mom would rather be beaten to a pulp than be alone. I've counted her being with 20 people in a month."*

Also emphasized in this group of young women were the profound mental health consequences of abusive family environments and of falling victim to other forms of violence. A high percentage of the women admitted to having serious mental health problems. Other topics which came up more often in this group were related to self-image, puberty and hormonal changes, and the impact of the media on their behavior and self-image.

San Luis Valley

Given that the women in two of the groups that were held in the San Luis Valley were participating in domestic violence groups, such violence was a principal topic of discussion. Though relationships with men were discussed in all of the groups, more emphasis was placed here on long-term relationships that had gone badly. Physical and especially emotional abuse were highlighted as men commonly put women down for being uneducated and incapable. Infidelity in these relationships was also mentioned frequently as was the impact of alcoholism. In fact, most of the substance abuse-related problems discussed by these groups concerned alcoholism rather than the abuse of other drugs.

> *"I was 16 when I got married, and I spent 17 years with a man that treated me like shit. It took a lot for me to get over that. I stayed for my kids, because they were young. I needed more self-esteem. And I didn't work, and I raised the kids. I was dependent on him, and he made me feel that I wasn't worth anything."*

> *"Alcoholism is real common in the Valley because there's not a lot to do. It happens to a lot of people."*

The poor quality of health care in the San Luis Valley was discussed at some length in these three groups. One complaint concerned the lack of competence of many providers, including their tendency to not listen to patients and not pursue problems thoroughly. A related issue concerned the lack of specialists in the area as well as a significant rate of turnover among providers, making for a high level of inconsistency in care. One woman complained that providers often stay no longer than a year.

> *"People do their residency here, and then they leave. We're the guinea pigs."*

Other topics that came up more frequently concerned the lack of access to free condoms, the confidentiality issues that arise in trying to buy them, and the conflicts that can be generated when trying to negotiate their use. Problems accessing sterile syringes also were at issue. An overall lack of entertainment was stressed in these groups, which was blamed, in part, for young people's tendency to use drugs and have sex. Abuse by the police was also emphasized, as it was in the Denver groups as well.

HIV-Infected Women

Two of the focus groups that were conducted consisted entirely of women who were living with HIV. As can be expected, this influenced the tenor of the discussions substantially. One set of topics concerned some of the mental health consequences of being HIV-infected. Feelings of depression, fear, and isolation were brought up by several of the women. Some said they felt rejected by family and friends and felt a real need to connect with others, gain emotional support, and have someone who would listen to them.

> *"It's like being isolated, like I don't have no family. I'm pretty much always by myself…no support system, and that doesn't help. It's like people are scared of me. I don't know what it is. They know I live there. I'm not always gone. And I'm scared, especially now that I found out I had full-blown AIDS and was over a million (*viral load*)."*

> *"It's like not feeling like a woman. Like you're singled out. Like there's nobody else out there like you…that's heterosexual and a woman. People treat you like… ooohh."*

Another common focus was on the medications that they were taking. Most saw the benefits of taking medications that would prolong their lives and keep them healthier longer, but dealing with the side effects of the medications was very difficult for some. Relying on public transportation while on medication was especially seen as problematic. With some drugs a person needs to avoid the sun. Also, given that diarrhea is such a common side effect as well as nausea, being on a bus for any length of time is very difficult. Several women mentioned how they missed appointments because they had to rely on the bus.

> *"Sometimes just having to get around to get papers signed can be a hassle. I have diarrhea so bad, and it takes me an hour-and-a-half to get home."*

Discussions about partners in some ways took on a different bent for the HIV-positive groups. Three of the women disclosed that they had been infected by their husbands, two of which never disclosed their status to them. Those currently in steady relationships said it was difficult to get their negative partners to use condoms to protect themselves. Others talked about the potential dangers involved in disclosing their serostatus to others. Three women talked about how their partners used the women's HIV status as a way of controlling them by threatening to tell others about it.

> *"My husband said he wouldn't be able to live if he found out he had it, and we have sex at least once a day. You'd think he'd want to cover it up. And I have a whole basket of condoms by my bed. He'll only use them if I'm close to my period."*

> *"It's damn hard to have to stop and tell. Then there's the rejection factor. You don't want to get rejected so you don't want to bring it up."*

In one of the two groups, the women were very disillusioned with the treatment they received, especially from a local service organization. They felt that priority was given to white gay men, and that women were discriminated against, especially if they have drug problems. Problems getting housing and other assistance were highlighted, with two of the women claiming to have received no assistance and one stressing how the apartment the organization put her in was in a dangerous and drug-infested neighborhood. Overall, the women felt that the number of services available from various agencies had declined.

"I've been trying to get an apartment through ____. They sent me to this place in a cruddy neighborhood. I said, 'I'm a woman. I'm an addict. And I can't be in this kind of neighborhood.' Just walking down the street there are all these people trying to sell you drugs. And I'm trying to stay clean, and they're telling me how I gotta stay clean to go up there, but then they're sending me to this neighborhood that's infested with bad people."

Finally, the groups talked about positive ways that they wanted to make a difference for themselves and others in spite of their HIV status. The topic of using themselves as examples to help encourage others to stay safe was brought up several times. Some wanted to help out their high-risk friends and family members, while others talked about how it was critical to talk to their children so they would be aware and not take risks. Speaking in front of groups to help raise awareness and to encourage others to be safe also was a suggestion from the groups. Finally, one woman stressed how important it was to empower oneself, particularly through education - including learning more about HIV as well as pursuing higher education - and proceed through life with confidence.

"My son is 16, and I don't think he'll ever have sex without a rubber, because he knows about me. I talk to my sons about it. They get some education in school, but I think they should have more."

PROGRAMMING NEEDS AND SUGGESTIONS

All of the focus groups were asked to discuss their ideas for programs and services that they felt would be most appropriate for women in light of the major life issues and risks that they had highlighted. Thoughts on HIV prevention and other HIV-focused programming were specifically elicited as well as those concerning other related services. Emphasis was continuously placed on the need for critical services such as those related to substance abuse, mental health, HIV care and prevention, and other health matters to be well-integrated, either by being offered in conjunction with each other or by being soundly linked through a referral system. With that in mind, such ideas as they pertain to HIV prevention, and, to a lesser degree, to care will be covered first. Many of these ideas, however, just as easily pertain to other key, and often more immediate, service needs such as those for substance abuse and mental health treatment. Therefore, they are repeated in briefer form in subsequent sections.

HIV-Related Programming

Groups

Ideas related to HIV programming that received the most attention concerned services that could be offered to women in groups. Such groups would offer necessary information related to HIV, risk reduction assistance, and, perhaps most importantly, emotional support. Suggestions that came up in the majority of the groups had to do with the kind of people who should lead and/or speak to the groups. Characteristics that seemed most important included that the leaders and speakers be women who were non-judgmental and straightforward.

Having them be people who the participants could relate to and respect, such as women who had confronted hard life issues themselves and had successfully gotten through them, seemed especially important as was having them be experts on the topics discussed. Incorporating leaders and/or speakers who are women living with HIV was thought to be a very powerful strategy for HIV prevention groups.

> *"You need to have someone there who has it, because most people think this isn't going to happen to me. But if they hear the stories about how it happened to me, then they'll think more. They need to hear about what taking the medication is like. I'm in the bathroom half the day."*

> *"Someone who had HIV came and talked to our class and it was scary. I thought about how I didn't want to go through that, especially if you want to have kids."*

A topic that most of the groups thought should be dealt with in a significant way was self-esteem. Learning to feel better about themselves through the group dynamic was expressed as being a fundamental part of effective HIV prevention for women. Encouraging independence, empowerment, and spiritual development were discussed as key pieces of this effort. Other group content suggestions concerned the integration of various issues into these groups, such as substance abuse, life skills, violence, and related health matters. Several women articulated the need for groups to be committed to improvement of the participants' life situations and not just be forums for commiserating and telling "war stories." One woman spoke of a seminar series for women that she attended in another state which she thought had been very useful and that could be used as a model. The series touched on many subjects that can be important to women including appearance, parenting, children, and depression.

> *"Women need someone to remind them to respect themselves regardless of the situation. That's where I slip up. I could be in a situation where I want to use a condom and the condom might be a couple of steps away, and I don't use it. I have to have enough respect for myself to say, 'Wait a minute. Right now I'm jeopardizing my life.'"*

Other suggestions for HIV-prevention and related groups were more structural in nature. Settings that are pleasant and/or tend to be places where participants may already frequent were mentioned, and having food seemed to be important to some. A few women felt it would be best to meet in groups with people they do not already know, stating that their friends may not be as inclined to be "brutally honest" and hold them accountable. One woman stressed how important it would be to start the groups with exercises that are meant to generate trust. Having rewards dinners and activities for groups of women who have completed a series of sessions also was mentioned as a good way to validate women's efforts to make improvements in their lives.

Aside from the above, some more specific suggestions were made for groups of young women and adolescents as well as for women who are living with HIV. Almost all of the

groups talked about children needing to learn about HIV, STDs, and related problems from the time they are in elementary school, before they are inclined to be sexually active. As mentioned above, the groups specifically expressed that sex education had to go beyond talking about abstinence and teach young people the skills they need to make safer choices and protect themselves. Teaching parents how to talk to their children about these matters also was stressed in several of the groups. Two other ideas that came up concerning groups for youth were the use of "scare tactics" (meaning showing them the suffering that HIV can cause) and the use of contracts through which young people make written commitments to have safe sex or remain abstinent. In exchange they receive certain incentives.

> *"If we have sex education in schools, why can't we have STD and HIV prevention. There are programs that have you sign things that say you're not going to have sex or unprotected sex during prom or drink and drive, and they're great!"*

> *"When young girls are going out there in that world before they get involved in this stuff. There are women who have been out there that could come talk to these young girls about what they've been through, and if they listen, it could save their life. If you give them that sense of self-esteem that they're about to throw away. Women have to know that they don't have to do that before it's too late. They don't have to stick a needle in their arms or make it with no man. And if you want to have sex with someone, then cool. Use a condom. It's just education."*

The two groups that were made up of women who were HIV-infected talked about some of their programming needs. The women expressed the importance of being able to meet with other women who were living with HIV and thought that there needed to be more such groups. According to them, substance abuse-related groups for positive women were particularly needed. Dealing with medications and their side effects, assistance with accessing services, and dealing with self-image and self-worth were all topics that were important to them. Issues of disclosure of HIV status also were discussed in some detail. Fears concerning being physically hurt and/or of being emotionally rejected by partners, friends, and family were especially important. Assistance with protecting partners and convincing partners to protect themselves was an issue for several of the women, as was helping their children to not "follow in their footsteps." Help in dealing emotionally with the grief associated with having a potentially terminal illness also was an idea that generated interest within one of the two groups.

> *"You need to educate people. Give them condoms. Help people to say that they have it and don't want to spread it."*

Individual Level Programming

Given that many of the women who are at high risk for getting or spreading HIV have serious interrelated problems stemming from histories of abuse, alienation, and substance use, the participants in most of the groups saw a need to have one-on-one support for such women.

The availability of professional counselors and therapists was stressed as critical for those in need, but some said that just having someone to listen to them and give them some guidance and information, whether they are professionals or not, was very important. Also someone to follow up with people who are dealing with certain issues such as HIV infection or high risk for infection, a history of STDs, or a history of substance abuse was stressed as a need in many of the groups. This would involve having someone to check to see how things are going and then offer any necessary assistance. Having client advocates also was seen as important to help women to maneuver within complex service systems and to defend them against system abuse. A mentoring system, especially for young women, also was proposed.

> *"There needs to be a place to go where women can get their needs met, where they have addiction counselors, mental health workers, therapists, psychiatrists ...someone who's going to listen to you...someone who won't discriminate against you. We don't have nobody like that."*

Other one-on-one intervention suggestions involved doctors and clinics, as the participants stressed that doctors should be talking to their patients about HIV and related health problems. One group had the idea of giving classes to women on subjects such as HIV, STDs, and how to talk to one's children before the new mothers leave the hospital after giving birth. Other suggestions included the provision of affordable or free methadone treatment to injection drug users who want to enter treatment and enforced counseling for people who are HIV-infected who are still putting others at risk.

Community Level Programming

Several suggestions were made about ways to impact communities around issues related to HIV. Raising community awareness was especially stressed as well as confronting community discrimination against people who are HIV-infected or who are at high risk. One group stressed how all communities needed to be addressed, not just poor neighborhoods and/or those with larger ethnic minority populations. Increasing outreach to at-risk populations and more widely distributing condoms, bleach kits, and crack kits in places where access needs to be increased also was stressed. Outreach testing for HIV in order to encourage more high risk people to test and offering incentives to people who test also were mentioned.

> *"You just don't hear about it in white folks' neighborhoods. According to statistics, the only people who smoke crack are low-income Black, Hispanic. You don't hear nothin' about Anglos and more Anglos smoke crack and shoot heroin. You just don't hear about it happening in the suburbs. It needs to be in all communities because it's not just the low-income communities. The other communities need it too."*

Many stressed the need for needle exchange and better access to sterile syringes through pharmacies to help prevent the spread of diseases such as HIV and hepatitis C among injection drug users. A drop-in center, especially for drug users, where people could go for materials, information, basic needs, assistance, services, and safe haven also was suggested by several of the groups. Having school staff act as resources for young people who may be at

risk also was mentioned by one group, as were "parties" in which people could become more familiar with safer sex strategies and materials in a fun way.

> *"Not long ago I was around someone shooting drugs, and they were even shooting drugs with the same needles, and they had barbs on them. You got to make it easier to get those needles…Have needles where they can get them easily."*

> *"We need a 24-hour safe place to be with others, a place where it's not scary, it's easy to access, where you can feel comfortable, where you can feel listened to and not afraid."*

Public Information

In spite of the fact that information on HIV and its prevention has been available to the public for many years, the women in each of these groups stressed the need for more education to help the public better understand the disease and to raise greater awareness around risk and at-risk groups. They suggested many forms of media as ways to disseminate information and highlighted various venues where they thought the information would reach the people who needed it. Television, radio, and newspapers were included as appropriate means for communicating statistics, other facts, and encouragement for protection, as well as means for advertising condoms. Several groups criticized the lack of condom commercials on network television and felt that more visibility might encourage their use at critical times. The group of young women could not understand how there could be so much sex on television and so many commercials for personal products related to sex and the reproductive system, but there were virtually no condom commercials on any station except MTV. In order to raise group and community awareness around HIV, some of the women suggested the increased use of speaker panels of HIV-infected women. Public information campaigns, especially around holidays, also were proposed. The dissemination of information at health clinics and places where women shop and go for services, as well as the availability of both confidential hotlines and chat lines were other ideas mentioned by the groups. One woman mentioned the need for better access to computers.

> *"We watch TV every day. Maybe they should heighten awareness. If people see commercials about condoms on TV, when they are in the moment they would use a condom."*

Women in the focus groups also called for the dissemination of specific types of information and/or information targeted at specific groups of people. Types of information included local, statewide, and national statistics; education on street drugs and how they relate to HIV risk and treatment; education and encouragement around the use of non-penetrative sex; and instruction on ways to increase sensation and excitement while using condoms. The women also thought that there needed to be more available information on where services, including HIV testing, can be accessed. Information on other related health issues also was requested. Specific groups that were cited as needing targeted information included heterosexual men, drug users, and youth. Medical providers also were mentioned as needing more information

and technical assistance around HIV in order to deal more effectively with HIV-infected and high-risk clients.

Other Suggestions for HIV Programs

A few other ideas for HIV-related services were offered that do not fit well into any of the above categories. One overall suggestion was that HIV prevention needed to be fun and appealing to people. Related to this was the need to offer incentives, rewards, and other "perks" to participants. Such perks for women who are in poverty could include basic necessities such as food and clothing for themselves and their families, or coupons and gift certificates to beauty salons, stores, and entertainment venues. The importance of facilitating access to services also was stressed. This would include meeting transportation needs with vouchers and bus tokens as well as providing child care at service venues. Encouraging couples to pursue HIV testing together was another suggestion as was the provision of housing for HIV-infected women and their families. It also was stressed that HIV prevention programs needed to encompass sound referrals to other related services.

> *"Make it fun. It's a very serious issue, but you have to be able to grab people's attention. Like that outreach we did with Urban Peak a few weeks ago. Summerfest. That got kids attention, and it held it. They were giving out free pops if you took a chlamydia test."*

Substance Abuse-Related Programming

Many of the suggestions discussed above in the section on HIV-related programming were not necessarily specific to HIV, but were discussed within the context of what integrated services should encompass. Therefore some of the suggestions are the same or similar as they pertain to programs addressing substance abuse, and, to some extent, mental health as well. This overlap includes already discussed ideas such as: 1) affordable and/or free methadone with fewer restrictions on access; 2) groups offering support, education, therapy, enhancement of self-esteem, and development of life skills; 3) well-trained, straightforward, and compassionate counselors/group leaders, preferably ones who have successfully confronted major life issues; 4) substance abuse treatment groups for HIV-infected women; 5) rewards dinners; 6) needle exchange and better pharmacy access to sterile syringes; 7) drop-in centers; 8) client advocates; and 9) sound referral systems.

Substance Abuse Treatment

As mentioned above, many of the women in the focus groups who had experience with substance abuse treatment felt that their needs had not been met adequately. One idea for improving treatment that was commonly expressed encompassed the need for quality and affordable treatment to be available "on demand." Given that most of these women are living in poverty, access to subsidized treatment is a must. They felt if they did not have to wait to get into subsidized programs, their chances of entering treatment and completing programs successfully would be much greater. Access to longer term treatment programs and especially inpatient treatment seemed particularly important for women who had been

struggling with addiction for an extended period of time and for women who needed to get away from their regular living environments if they were going to succeed.

> *"I was blessed because I got to go to a program that was strictly for women. They deal with the codependency issues and other stuff, where you can sit and talk about how you feel and you're not judged. The lady that runs that, her daughter died of alcoholism and addiction, so she really has a good grasp of things. She doesn't kiss your ass, but she has a good understanding of how you feel. It's for indigent women. You have two weeks to find a job, and you have to work full time. You have therapy every day with a group. It's just like a house. It's like normal living. You don't feel like you're in an institution or a drug treatment center. You cook and you clean and you have one-on-one therapy once a week. And the door is always open. It could be 3:00 in the morning and they get out of bed and talk to you. You have to work cause when you start paying bills and can buy your food you start to feel good about yourself. When you don't have to have a man to do stuff for you. Even the little shit can help build self-esteem. You can live there up to two years. You have to commit to 90 days. You learn how to build a structure outside the home, like going to an NA or AA meeting three times a week."*

Longer term detox in environments that are safe for women also was suggested. The women especially thought that effective aftercare and follow-up was key to success in going into and staying in recovery, given that when a person finishes a program she needs support and assistance in getting "back on her feet," staying "clean," looking for work, finding housing, paying bills, caring for children, etc. Other thoughts about treatment included the need for maintaining confidentiality, especially for women who are living with HIV. People also mentioned the need to get women addicts into treatment rather than putting them in jail. Since losing children to Social Services was so common among women in several of these groups, the need to get women the necessary help to keep their families intact was expressed. This not only involved access to treatment programs that allow children to live with their mothers, but also access to client advocates and legal assistance in cases where children may have been taken unfairly due to discriminatory assumptions about the mothers.

> *"You definitely need aftercare…a counselor or a mentor."*

Other Substance Abuse Related Suggestions

Two other suggestions concerning substance abuse programming that were not directly related to treatment also were offered in the groups. Women discussed sometimes getting in dangerous situations while they were "high," especially during the night, and they had no place to go. Therefore the need for shelters that will accept people at all hours, even if they have been using drugs and alcohol, was mentioned. Also, the youth group stressed that anti-drug campaigns, especially those that insisted on total abstinence from drug and alcohol use, were not effective. In light of this, their call was for campaigns that were more realistic or more in touch with the realities of young people's lives.

"…some make it sound so evil that you're tempted to check it out. And some want to see what it's like because it's a huge unknown."

Mental Health and Abuse-Related Programming

Mental Health Service Suggestions

Given that mental health problems such as depression and low self-esteem seemed to be at the root of many of the other problems discussed, such as substance abuse and HIV risk, the call for better access to affordable/subsidized mental health care was quite strong in the focus groups, as was the need to integrate mental health care with other types of services. This call included a need for better access to medications for those with biologically-based problems, more dual-diagnosis providers to serve people who also have substance abuse problems, and counselors with the proper expertise to deal with the tough life issues many high-risk women face.

"We need mental health services…somewhere you can go in and get therapy, one-on-one. Mental health is a huge one."

The women expressed the importance of being able to meet in groups with other women to discuss their issues. Since the lack of self-esteem was such a prevalent theme in the groups, the women felt that it needed to be a major focus in groups for both adult women and girls. Offering both the emotional and spiritual support that women need to understand what they are worth and their right to self-fulfillment, independence, and self-protection were key elements for these groups. Stress management and coping strategies also were suggested topics. As mentioned previously, having women who had overcome a lot in their lives lead these groups was stressed as important, as they can provide examples to the other women of what is possible. The HIV-infected women expressed a need for these groups to also help them deal with grief.

"Women need self-esteem. They need to be able to get into a group and hear that they're worth something."

Other suggestions related to mental health included the need for client advocates, follow-up, and information about and referrals to other services. A "buddy" system, which provides someone who would be available when women need to talk and be listened to, and a mentoring system for younger women, also were mentioned as good ideas. In the two HIV-positive groups, suggestions were made for providing "perks" or gifts to women that would make them feel better about themselves. Ideas included trips to beauty salons, new clothes, and cosmetics.

Abuse-Related Programming

Clearly many of the mental health problems that the women discussed stemmed from histories of abuse, either as children or adults and, often, both. Therefore, mental health services are vital to helping women deal with this history and some of the common consequences such as

substance abuse and HIV risk. Other ideas discussed in the groups that were related to the violence many women face concerned the need for places women can find refuge. These would include more shelters designed for victims of violence. Since some of the women stressed how such violence often occurs in conjunction with substance use and often at night, having a place they can go to at any hour and even if they have been drinking or using drugs also was seen as important. Financial assistance for victims of abuse also was suggested as women's ability to work often is jeopardized. A final suggestion concerned the need for stricter investigation of abuse cases and stricter prosecution and more extensive punishment of perpetrators. This seemed to be especially needed in the case of childhood sexual and physical abuse given that children are so vulnerable and virtually powerless in attempts to defend themselves and their rights.

> *"(We need) a place to run to get you off the street and away from him. A lot of times women they run out the house at 2:00 a.m. I have, and I end up staying out smoking crack or getting drunk or going to the bar or just walking cause they don't have nowhere to go."*

Health Care Program Needs

Affordable health care and affordable health insurance were needs that were expressed by women in the focus groups. Many of the Denver-based women were accessing subsidized care at facilities such as Denver Health Medical, but access to medications, specialists, and other necessities such as nebulizers, oxygen tanks, and wheelchairs was still seen as problematic. Free clinics such as Stout Street Clinic were discussed favorably, but the need for more such clinics, especially one just for women, was emphasized. One suggestion was made concerning outreach clinics, which could make at least some necessary services more readily accessible.

Provider characteristics were stressed in the groups as the women saw the need for more clinicians who were non-judgmental, non-discriminatory, conscientious, and sensitive. Providers were needed that would take more time to explain things to clients and listen to their ideas and concerns. Being able to access care from the same provider also was emphasized, given the importance of knowing a client's in-depth history and the importance of established rapport in meeting people's health care needs. Provider training also was suggested to both increase their medical expertise and to make them more competent in dealing with people in a respectful way.

> *"We need doctors that will listen to you and explain things to you until you understand and not make you feel like a moron."*

> *"A steady doctor knows your whole medical history. They know your family. They know what problems you could be having. You're more comfortable with them. And you'll give them more information."*

Other health-related suggestions brought up by women in the groups included the need for education and the dissemination of information on health issues. Having providers come talk

to groups about particular health problems was one well-received idea. Women who are living with HIV stressed a need for financial assistance to obtain medications and supplements, such as vitamins, which are not covered by Ryan White funds.

Services Related to Basic Needs

Affordable housing was an expressed need in all of the Denver-based focus groups and in the Boulder group as well. Programs that provide assistance to women in finding housing in safe neighborhoods were recommended highly. According to the groups, access to housing should not be influenced by whether or not a woman has young children and should not carry restrictions on the acceptance of spouses. Women who were homeless or in very unstable housing situations stressed the need to access stable housing, not just have access to temporary shelters or motel vouchers. Women who were HIV-infected expressed a need for housing specifically for them and their families.

> *"Look at all these empty apartments. They could give them to people without families or people with children."*

Having more shelters that can accommodate women safely also was highlighted as a need. Shelters that did not have restrictions on what hours a person could be there was said to be important, as many shelters do not allow people to stay there during the day. As discussed above, having a safe haven that is available 24 hours a day, seven days a week for crisis situations would alleviate some of the shelter-related problems associated with domestic and other forms of violence. One woman suggested that even having churches open at all times could be very useful when women are frightened and need to escape their immediate circumstances.

Many of the women participating in the focus groups had substance abuse problems and criminal records. Most were not employed currently. Therefore programs were consistently recommended that would help women with life skills and with taking on new responsibilities. Many of the women are required by Social Services, the judicial system, or other agencies to assume responsibility for certain tasks at a pace they are not prepared for. Looking for gainful employment, especially if they are just beginning recovery from an addiction and/or they have criminal records was said to be very difficult. Programs that would allow women to ease into responsibilities and offer assistance in matters such as looking for work, keeping a budget, making appointments, and paying bills could be very helpful, as would agreements with certain employers to hire women with records and offer living wages.

> *"We need a place where responsibilities are placed on people gradually and not all at once when people aren't ready for it."*
>
> *"They need some kind of program where they give you steps 1 through 5. This is what you need to do and you got somebody to help you get through them."*

As mentioned above, needs for transportation to get to appointments and jobs and to access services was mentioned frequently during the focus groups. Programs that can offer bus

tokens or arrange for other forms of transportation if taking the bus is problematic can be very useful. Agencies that can provide child care while women are accessing services and assistance with acquiring quality child care for women who are employed, seeking employment, or going to school can greatly help women take care of their needs. Some women also mentioned the need for financial assistance, food, and clothing. In two of the groups, the importance of offering entertainment was expressed. In one case it was so that young people could have fun while engaged in activities that are safer than doing drugs and having sex. In the other case, it was suggested as a way for women to alleviate stress. A final need that was expressed in several of the groups was the better dissemination of information on what services are available for women in various areas, though no specific suggestions were made as to how this should occur.

CONCLUSION

This study constitutes an important piece of formative evaluation, a qualitative approach to gaining consumer descriptions of their complex and interrelated life issues with a degree of depth not possible using only quantitative methods. Such an approach also gives service providers an opportunity to get consumer input on what clients see as their needs, how best to meet those needs, and how service systems often fail them given the current structure and dynamics of those systems. Offering women a chance to have their voices heard and their opinions considered can be, in itself, empowering, as long as they are able to see that those opinions have been taken seriously and their ideas incorporated into the development of programming.

The women participating in these focus groups were chosen to participate based on what is known through research and through the work experience of epidemiologists and key service providers about the characteristics of women who are at highest risk for HIV and the other health-related problems described in this report. The focus group participants all were women who were accessing or have previously accessed various types of services and were able to offer critical insights contributing to an evaluation of those services. The group participants did not include women who may have similar needs but do not seek help. Furthermore, though many strengths, assets, and "success stories" were exhibited by the participants, the content of the discussions did not focus on those assets and successes to a great extent, nor were groups conducted with women who had made major life changes to the extent that they no longer needed to access services. However the body of knowledge that these women have offered here attests to one of their greatest assets, which is an in-depth and complex understanding of their life circumstances and the circumstances of women like them and what changes need to occur for those circumstances to improve. Further research could help to gain a better understanding of both women who are unable to overcome barriers to accessing assistance and women who have successfully overcome great odds and the strategies that they have used to do so.

A principle purpose of this summary document is to bring to light the depth and complexity of the life issues confronted by the participants in these 10 focus groups and the many women living under similar life circumstances. Though a fair amount of diversity existed within and

especially among the various groups in terms of age, ethnicity, health status, and places of residence, many commonalities surfaced, contributing to a strong statement of need that must not be ignored**.** That statement most clearly emphasizes the fact that substance abuse, mental health problems, violence and abuse, poverty, discrimination, and the risk for getting or spreading HIV are interconnected so extensively, and our mostly disconnected service systems are poorly equipped to deal with these multiple needs as effectively as they could. The need for the integration of services currently is being discussed at many levels, including among federal agencies such as the Substance Abuse and Mental Health Services Administration, the Centers for Disease Control and Prevention, and the National Association of State and Territorial AIDS Directors who met on this subject in February 2002. Future guidance from federal partners will contribute to Colorado's efforts to develop new collaborations among various agencies.

For those who work on the "front lines" with women who are at high risk for HIV and other health-related problems, there may not be much that is new in this report. However, a certain validation of what they know arises from the powerful and often very similar testimonies of so many women. For those who may be more removed from the life circumstances of high-risk women, the report may serve as both a "reality check" and a call to take appropriate action to help alleviate those life circumstances.

RECOMMENDATIONS

After reviewing and discussing the results of the 10 focus groups, members of the Colorado Women's Health Advocacy Coalition developed the following recommendations. These recommendations do not necessarily reflect the opinions of any other entity.

Public Health and Integration of Services

- Encourage collaborations among government agencies and community-based organizations. Simplify access to related services through common intake forms and procedures and a central database. Develop appropriate interagency relations and ensure a sound referral system.

- Collaborate in the establishment of agencies through which a variety of services can be offered in locations that are easily accessible to high-risk women. Such services could include substance abuse treatment, mental health counseling, HIV prevention, housing assistance, job-related services, domestic violence assistance, family planning services, other social services, and support groups. These services must be offered in a culturally competent, client-centered manner, building on the assets of individuals and finding supports that work best for each person**.**

- Promote the establishment of drop-in centers within high-risk communities that offer necessary services on a rotating basis.

- Establish a coordinating committee with representatives of mental health, substance abuse treatment, and HIV prevention to ensure mutual capacity-building and integration of services. Develop regulations for providers based on such integration and allow for the development of specializations in these arenas that operate under mutually agreed upon guidelines.

- Organize a round table discussion bringing together service and care providers as well as policymakers from mental health, substance abuse treatment, public health, homeless advocacy, domestic violence, victims' assistance, local government, the state legislature, and other agencies. Focus attention on raising awareness about women's issues and on gaps in service, filling those gaps, and integrating services.

- Develop a centralized database system through which public monies designated for public health and related service provision can be tracked. These would include federal funds coming into the state of Colorado as well as those provided by the state and local governments. Such a system would make it possible to more readily obtain information on which agencies are funded to provide particular services and for whom. It would also facilitate collaboration as well as the analysis of the effective use of public dollars.

- Establish support groups in a variety of settings through which women can gain and share information, raise awareness, address their issues and the roots of their problems, seek solutions for life problems, improve their self-esteem and assertiveness, provide mutual support, and learn to recognize and build on their assets.

- Promote a team approach to service provision that could be coordinated by case managers.

- Ensure that agencies are reflective about which people they can and cannot best serve. Referrals should always be made to more appropriate agencies when program participants' needs are not being met.

- Provide advocacy for those who are most marginalized and have the most trouble maneuvering within service systems. Encourage agencies to provide child care services and transportation assistance (e.g., bus tokens, taxi service, etc.) whenever possible.

- Based on extensive research on the public health benefits of syringe exchange programs, promote further public discussion of those benefits and barriers to implementation.

- Develop life skills and work-related programs for those coming out of substance abuse treatment and correctional facilities.

- Promote the establishment of 24-hour drop-in centers that offer a safe retreat for women at risk.

Substance Abuse Treatment

- Expand the capacity to provide subsidized inpatient substance abuse treatment for women that offers dual-diagnosis services (integrated substance abuse and mental health treatment), aftercare, medical detox, life-skills training, and HIV prevention.

- Expand the capacity of both residential and non-residential substance abuse treatment to provide services specifically for women.

- Encourage treatment options that include children, especially for single mothers who need extended and/or inpatient treatment.

- Expand the availability of treatment slots that can be accessed immediately. High-risk women with immediate needs should not be put on waiting lists.

- Incorporate harm reduction therapies in the treatment of women with addictions.

Mental Health

- Integrate mental health and substance abuse treatment for those with dual diagnoses.

- Expand criteria for qualifying for subsidized mental health services, and expand the capacity for serving women in poverty.

- Develop group settings where women can share experiences and support each other in learning new skills.

- Expand access to treatment that is not time-limited by payer requirements.

- Incorporate harm-reduction therapies in the treatment of women with addictions.

Capacity Building, Quality Assurance, and Cultural Competence

- Provide harm-reduction training and other forms of capacity building to service and care providers to help raise awareness of the multiple, inter-related issues high-risk women confront and the difficulties they face in making life changes and in getting their needs met.

- Increase the capacity of service providers to recognize the symptoms of depression and to know how, when, and where to refer people with depression.

- Assess agencies' capacity to provide services that are effective and culturally competent.

- Ensure that high-risk women are involved in the planning, implementation, and evaluation of programs that are meant to meet their needs.

- All agencies providing services to high-risk women should offer staff training on conducting risk assessments for issues such as HIV, domestic violence, substance abuse, mental illness, etc.

- Encourage staff development for providers working with high-risk women to promote a team/collaborative approach to client care.

Research

- Conduct focus groups with case managers and service providers to better understand barriers they confront in providing services to high-risk women.

- Gather qualitative information from women who have been successful in overcoming extremely difficult life circumstances, focusing on their assets and strengths. Also develop strategies to gather information from women who are unable to overcome barriers to accessing needed services.

- Conduct in-depth interviews and assessments with people newly testing positive for HIV.

- Conduct research to determine the extent of the problems discussed in this report.

Political Action

- Challenge political action groups and policymakers to address the larger life issues of poverty, discrimination, and abuse that often put women in high-risk situations.