A TALE OF SIX CITIES:

PARTNER SERVICES THROUGH THE EYES OF GAY MEN AND OTHER MEN WHO HAVE SEX WITH MEN

Susan Luerssen, PhD
George Ware, MS

STI/HIV Prevention Program
Colorado Department of Public Health and Environment
4300 Cherry Creek Drive South
Denver, Colorado 80246

August 2013

For further information call Regina Charter at 303-692-2747
Introduction

Since the beginning of the AIDS epidemic and then, more recently, with the increased spread of syphilis, many gay and bisexual men have had the experience of being contacted and interviewed by people from state and local health departments who provide partner services (PS). These experiences have been both positive and negative, but when clashes have occurred, they have often stemmed from perceived conflicts between the role of public health to prevent the spread of disease and the needs of individuals for compassion and privacy. Problems have also arisen when common approaches to PS have not been seen as effective and/or appropriate by those receiving the services.

In 2007, Research and Evaluation (R&E) staff at the Colorado Department of Public Health and Environment (CDPHE) conducted a needs assessment for the Mid-America Prevention Training Center (MAPTC) with Disease Intervention Specialists (DIS) who conducted PS in various regions and cities across the MAPTC service area. Results of that assessment showed that, overall, DIS face a number of barriers in trying to engage gay men and other men who have sex with men (MSM) in PS, more so it seemed than with any other population. In response to this information, the MAPTC secured funding in the fall of 2012 from the Centers for Disease Control and Prevention (CDC) to conduct a formative evaluation consisting of focus groups held with gay men and other MSM within their service region. This evaluation was designed to gain valuable input from these men about what PS should include, how they should be conducted, and what the providers of these services need to know to be most appropriate and effective when working with gay men and other MSM.

Methods and Participant Sample

Soon after funding was secured, MAPTC staff decided that the formative evaluation would target men in the following six cities within the MAPTC service region, given their large and diverse MSM populations: St. Louis, Nashville, Chicago, Columbus, New Orleans, and Denver. STI/HIV Prevention Program (SHPP) staff met with MAPTC staff to discuss the format and content of the evaluation, and, based on those discussions developed the focus group topic guide. The topic guide was designed to explore subjects such as: 1) the nature and dynamics of the gay community in each area; 2) community norms related to HIV risk behaviors and disclosure of HIV status; 3) information that gay men and public health providers need to understand about each other in order to improve communication; 4) impressions that these men had about PS as well as experiences that they had with those services; 5) what PS should comprise in order to be perceived as beneficial to the people receiving the services; 6) what topics should be included in a course for PS providers to better engage gay men and other MSM; and 7) what other services should be available to gay men and other MSM at high risk or living with HIV.

The SHPP staff contacted agency partners in each of the selected cities to arrange the groups and recruit participants on behalf of the MAPTC. It was requested that participants be MSM who had experienced PS (ideally within the previous five years) or who knew a significant amount about those services. It was also requested that the participants, to the extent possible, be representative of the local HIV epidemiological trends. In all, eleven focus groups and one interview were conducted with a total of 101 participants. These groups were facilitated by a
SHPP staff member from CDPHE. Staff from local agencies in each city assisted with note taking during the groups. The discussions were also digitally recorded, transcribed, and analyzed. Table 1 shows some basic demographic characteristics of the participants.

Table 1: Demographic Overview of Evaluation Participants

<table>
<thead>
<tr>
<th>CITY</th>
<th>AGE RANGE</th>
<th>SEXUAL ORIENTATION</th>
<th>ETHNICITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>St Louis</td>
<td>20 – 29 = 3</td>
<td>Homosexual = 13</td>
<td>African American = 12</td>
</tr>
<tr>
<td>N = 17</td>
<td>30 – 39 = 3</td>
<td>Bisexual = 3</td>
<td>White = 5</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 5</td>
<td>Straight = 1</td>
<td>Latino = 0</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 5</td>
<td>Transgender = 0</td>
<td>Mixed = 0</td>
</tr>
<tr>
<td></td>
<td>60+ = 1</td>
<td>Other = 0</td>
<td>Unknown = 0</td>
</tr>
<tr>
<td></td>
<td>Unknown = 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nashville</td>
<td>20 – 29 = 10</td>
<td>Homosexual = 12</td>
<td>African American = 12</td>
</tr>
<tr>
<td>N = 13</td>
<td>30 – 39 = 0</td>
<td>Bisexual = 1</td>
<td>White = 0</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 0</td>
<td>Straight = 0</td>
<td>Latino = 1</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 2</td>
<td>Transgender = 0</td>
<td>Mixed = 0</td>
</tr>
<tr>
<td></td>
<td>60+ = 1</td>
<td>Other = 0</td>
<td>Unknown = 0</td>
</tr>
<tr>
<td></td>
<td>Unknown = 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chicago</td>
<td>20 – 29 = 5</td>
<td>Homosexual = 13</td>
<td>African American = 20</td>
</tr>
<tr>
<td>N = 22</td>
<td>30 – 39 = 2</td>
<td>Bisexual = 4</td>
<td>White = 0</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 10</td>
<td>Straight = 3</td>
<td>Latino = 5</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 3</td>
<td>Transgender = 2</td>
<td>Mixed = 1</td>
</tr>
<tr>
<td></td>
<td>60+ = 1</td>
<td>Other = 1</td>
<td>Unknown = 2</td>
</tr>
<tr>
<td></td>
<td>Unknown = 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denver</td>
<td>20 – 29 = 3</td>
<td>Homosexual = 22</td>
<td>African American = 2</td>
</tr>
<tr>
<td>N = 28</td>
<td>30 – 39 = 7</td>
<td>Bisexual = 3</td>
<td>White = 16</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 11</td>
<td>Straight = 0</td>
<td>Latino = 5</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 4</td>
<td>Transgender = 0</td>
<td>Mixed = 3</td>
</tr>
<tr>
<td></td>
<td>60+ = 1</td>
<td>Other = 1</td>
<td>Unknown = 2</td>
</tr>
<tr>
<td></td>
<td>Unknown = 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Columbus</td>
<td>20 – 29 = 10</td>
<td>Homosexual = 9</td>
<td>African American = 5</td>
</tr>
<tr>
<td>N = 14</td>
<td>30 – 39 = 2</td>
<td>Bisexual = 4</td>
<td>White = 4</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 1</td>
<td>Straight = 1</td>
<td>Latino = 1</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 0</td>
<td>Transgender = 0</td>
<td>Mixed = 4</td>
</tr>
<tr>
<td></td>
<td>60+ = 1</td>
<td>Other = 0</td>
<td>Unknown = 0</td>
</tr>
<tr>
<td></td>
<td>Unknown = 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Orleans</td>
<td>20 – 29 = 3</td>
<td>Homosexual = 6</td>
<td>African American = 4</td>
</tr>
<tr>
<td>N = 7</td>
<td>30 – 39 = 0</td>
<td>Bisexual = 0</td>
<td>White = 3</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 3</td>
<td>Straight = 0</td>
<td>Latino = 0</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 1</td>
<td>Transgender = 0</td>
<td>Mixed = 0</td>
</tr>
<tr>
<td></td>
<td>60+ = 0</td>
<td>Other = 1</td>
<td>Unknown = 0</td>
</tr>
<tr>
<td></td>
<td>Unknown = 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>20 – 29 = 34</td>
<td>Homosexual = 75</td>
<td>African American = 55</td>
</tr>
<tr>
<td>N = 101</td>
<td>30 – 39 = 14</td>
<td>Bisexual = 15</td>
<td>White = 28</td>
</tr>
<tr>
<td></td>
<td>40 – 49 = 30</td>
<td>Straight = 5</td>
<td>Latino = 8</td>
</tr>
<tr>
<td></td>
<td>50 – 59 = 15</td>
<td>Transgender = 2</td>
<td>Mixed = 8</td>
</tr>
<tr>
<td></td>
<td>60+ = 5</td>
<td>Other = 2</td>
<td>Unknown = 2</td>
</tr>
<tr>
<td></td>
<td>Unknown = 2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Community Norms

Focus group discussions began with the facilitator asking the participants in each city to describe the local gay community. Topics pursued included: the level of “gay friendliness” and acceptance of gay men as perceived by the participants; the nature of diversity, segregation, and integration within the community and among its subpopulations; the means that men often use to find sex partners, with a particular emphasis on Internet “hook ups”; and substance use and abuse. Participants in all of the cities emphasized the diversity of the various gay communities, often manifest in the presence of various cliques that were segregated from each other. These groupings were based on factors such as age, ethnicity, levels of being “out”, gender identification, gender expression, geographic areas, and body types (e.g., bears, kinks, jocks, etc.). Participants from St. Louis and Columbus stressed this segregation more than those from other cities. One participant from St. Louis expressed concern about the lack of conversations among gay men and how that led to missed opportunities to understand the community as a whole. A New Orleans participant stressed that the gay community there was highly diverse and that almost any gay man could find a niche there. However, he also emphasized that New Orleans was very “cliquey”. Participants from Chicago stressed that, more recently, men of different ages and ethnicities were socializing more with each other than they had before, partly because there were not that many places for gay men to socialize.

Overall, participants reported that it was much easier for gay men to be open about their sexual orientation now than compared to earlier years. This seemed to be especially true for younger men. Participants in Denver, New Orleans, and Chicago stressed that their cities were more accepting of the gay community than the participants in others cities and that the gay communities were relatively large and open. However, they also stressed that one had to be careful about expressing one’s sexual orientation in certain parts of those cities. One participant in New Orleans emphasized how gay men still had to be careful and that hate crimes still occur. Participants from Columbus described the city as not being “sex positive” in terms of openly encouraging sexual expression. They said that sex was not talked about openly, thus driving sex underground and encouraging high risk behavior as well as shame. All of the groups recognized stigma as a factor affecting gay men everywhere to some extent. One person from Chicago and another in St. Louis stressed that stigma often keeps men, especially African American gay men, from seeking medical care and accessing needed services. Several conversations in the various focus groups dealt with men who were not openly gay or who were on the “down low”, meaning that their sexual activities with other men were covert. This seemed to be a more common phenomenon among African American men than White men with participants stressing that gay Black men were not as accepted by their communities as White men. One participant in New Orleans, however, stressed that the whole meaning of being on the “down low” had changed for many men, and that, among young men, it had become something of a fad to label themselves as such without really understanding the meaning of the term.

Participants in all of the focus groups stressed that casual “hook ups” and anonymous sex were extremely common in all of the cities, with men finding sex partners at bars, bathhouses, and parties. Men especially use the Internet and phone-based applications to find sex partners. One participant said that a person can find anything he wants, including having sex “delivered to your door”. Another participant mentioned that, “You almost never see anyone online that is just
looking for someone to go to the movies with them.” Two others stressed that there are many men who would prefer to get into longer-term, steady relationships but do not really know how to go about it. On-line “hook-ups” were said to make it easy to be secretive about one’s sex life.

Condoms were not commonly used in these casual and anonymous encounters according to the participants, with some saying that those who want to practice safer sex are often rejected by other men on-line. One participant thought that older men were more inclined to have safer sex than younger men. Two from St. Louis stressed that in Missouri it can be very difficult for young people to access condoms due to pharmacy practices, school regulations, and program restrictions limiting distribution to those 21 and over. Participants from other groups also added that many men just do not like condoms due to diminished sensations and feelings of decreased intimacy.

Participants in the focus groups stressed special concern for younger gay men who they described as coming out at younger ages, having many sex partners, frequently accessing the Internet to find sex partners, getting involved with older men with more power and resources, and not practicing safer sex. Young men were seen as not equipped to protect themselves from disease, but hard to reach with health-related messages.

Most of the anonymous and casual encounters discussed by the participants were said to be associated with alcohol and drug use, which many said deterred condom use. Alcohol and methamphetamine were the most commonly used according to the participants. Marijuana, crack, cocaine, and heroin were also mentioned as some gay men’s drugs of choice. One participant said that people were high when having sex most of the time. Another stressed that outside of the bars, there was no place for gay men to socialize. Participants in one city spoke of how readily available all drugs were and how interconnected they were to the sex that was occurring. Participants from New Orleans emphasized that alcohol and drug use were especially prominent in their city. One described New Orleans as “the drinkingest city in the world”. Another stressed that people came there “for decadence”. A third man remarked that New Orleans is a tourist city where people come to party and do not want to think about their actions.

**HIV-Related Norms Across the Region**

Several norms specifically related to HIV were also discussed by participants in the groups. One topic that arose in most of the groups was that many gay men had become complacent about HIV, especially because of the effectiveness of HIV medications. Others were said to not value their lives very much, had a “you gotta die of something” attitude, and/or did not think about HIV at all. Several gave examples of men disclosing HIV status to a partner with the partner responding that he did not want to know the person’s status. Many participants stated that many gay men thought that HIV was a manageable disease, much like diabetes. It was something for which one could “just take a pill” and everything would be okay. However, one participant disagreed that such an attitude was widespread. Another stated that many younger men do not see the seriousness of the disease, because most of them had not lost friends to AIDS as many older gay men had. One participant complained that even though syphilis and other STD rates were very high in his city, many do not hear that information and do not have a sense of concern about those rates. Others remarked that among young gay men, the sense of invincibility takes
over, and they think they will not get HIV no matter how high risk their behavior. On the subject of viral load suppression, participants emphasized that many interpret the term “non-detectable” as meaning that the virus will not be transmitted. Some were said to use this as a reason to not disclose their HIV positive status. One participant advised that public health providers should be having the discussion about viral load with clients on a regular basis, and they should consider issues of viral load in conversations about risk. Another spoke of a friend that would not take HIV medications “because they would make him flabby”, which was more important to him than staying well. Others thought the news about the effectiveness of such medications had not reached many people.

Overall, participants in the focus groups thought that HIV was not discussed much in their communities. However, some participants in four of the groups said that they had heard people discussing HIV in various venues including at bathhouses, parties, and on-line. One participant stressed that the topic “kind of kills the moment”. A provider participating in one of the groups said that he does hear people talking about it more, and, increasingly, clients are coming to him for condoms. Another participant mentioned that when men are talking about it with potential partners, “they’re looking for more than sex. If they don’t talk about it, it’s just the sex.”

Participants were asked about HIV-related messages that are reaching gay men and other MSM in their communities. Many said they did not hear many messages about it. One participant observed that one might see advertising at gay bars, but otherwise, HIV awareness advertising was not seen. Others also spoke about how HIV was often in the media years ago but no longer. Several said that the only messages out there are coming from health departments and other agencies and not from gay men. In one city, participants discussed that the main prevention message was still “use a condom every time”. One observed that the prevention messages did not fit the reality that gay men are living in, emphasizing that a harm reduction approach to safer sex would be more effective. Another participant in a different city agreed saying that “everyone knows they should use a condom, but they don’t choose that option all the time. It would be great, but it’s not true.” Several others talked about how people just were not listening to the messages that are out there. One participant thought that there was a lot of misinformation reaching the community, highlighting information about pre- and post-exposure prophylaxis that “allowed” people to be unsafe. Another said that he got all of his prevention messages from friends and family who constantly reminded him to be safe. All of the groups agreed that there are no messages out in their communities encouraging men to notify partners of their HIV status in general or about PS in particular.

The topics of disclosure and non-disclosure of HIV status was widely discussed in all of the focus groups. The overall consensus was that HIV status was rarely talked about in these six communities, although many in the groups said that they were either very open about their HIV status or that they always disclosed their status to sex partners, even though many of the partners neither asked nor wanted to know. Many participants agreed that disclosure should happen. Many also said that they had rarely been asked their status by a sex partner. Most non-disclosure was said to happen in the context of anonymous or casual hook ups at bars, parties, bathhouses, and other public sex environments. In these cases, the sex was the priority and the norm was “don’t ask, don’t tell”. When people thought about HIV at all in these situations, much of their unsafe behavior was rationalized by assumptions that sex partners must have the
same HIV status as their own or they would not be engaging in the activity, and, if they did not, they knew what they were getting into. Also, in these circumstances, people rarely felt an obligation to share anything with someone they did not expect to see again.

Disclosure, and lack thereof, on the Internet was widely discussed. Some of the participants said that they disclosed their HIV positive status on the Internet, but thought that the practice was rare. Participants discussed that many men who are living with HIV who are looking for partners online either do not mention HIV at all or they lie about their status, a practice they thought was extremely common. When asked for the reasons why people do not disclose, not surprisingly, the most common reason was fear of rejection by partners, although some pointed out that fear of rejection online was not as important because a person can quickly move on to the next person. Many participants felt that positive HIV status was still highly stigmatized in the gay community. Many stressed that fear of being stigmatized and shunned by others, including their families and their communities, was a big factor influencing non-disclosure. Some participants emphasized that many men do not know how to have the conversation. One participant said it is especially hard to disclose when a person first finds out they are HIV positive because they feel an urgent need for privacy. Another stated, “Disclosing is like coming out again. When you have to explain it over and over, it’s exhausting”. Although most of the focus group participants were living with HIV, many did not seem to know specifically whom they had contracted it from. As one young man said, “No one told me when they gave it to me.”

In four of the focus groups and most often in the two groups held in St. Louis, the issue of state laws against non-disclosure was raised, especially in the context of how they influenced disclosure and HIV testing. Several in St. Louis said that they knew of many people who had been prosecuted for not disclosing their positive HIV status to sex partners. One stated, that because of the law, he disclosed on every website that he used to find partners to make sure everyone knew. Unfortunately, some St. Louis participants stated that they knew many people that engaged in very high risk behavior but would never get tested for HIV because of the laws. One said that he had often heard the phrase “Get tested, get arrested” which expressed a sentiment that if people get tested for HIV, then they would have to be more responsible when they have sex, something some would rather avoid. Another participant shared that as a person who had been accused under the law that “it is the worst feeling”. He thought that criminalization needed to be discussed more among gay men.

Such HIV laws were only one of the reasons that participants cited as keeping some gay men from testing for HIV. Participants thought that many gay men did not test regularly, if at all, and therefore, many did not know their HIV status. Some were said to not want to know their status or were afraid of finding out they are positive. One participant said that, “People think that if they don’t know, it doesn’t exist.” Another pointed out, “They still don’t want to hear they have it. And then they claim they don’t have it.” This was brought up in other groups as well. In one city, participants spoke of the large number of people that were finding out they had HIV when they were already sick with AIDS because they had not tested for many years. Another reason participants gave for lack of HIV testing among gay men was that many people do not want to be seen by others at testing locations because people will think they have HIV.
**Partner Services: Barriers, Impressions, and Experiences**

**Barriers.** Most of the focus group conversations centered around the participants’ impressions of and experiences with PS as well as their suggestions for making such services more appropriate and effective. Part of the discussions focused on barriers to having those services occur in the first place or having successful results when they do occur. One major barrier to PS cited by participants in all of the groups was that most people do not know about the services or their purpose and are surprised when they are contacted after their HIV diagnosis. Participants further stressed that people should know ahead of time that someone will be contacting them and why. One person commented that, “A lot of what DIS do is not explained, and when people do not know how something works, they do not know how to utilize the service.”

Another barrier to PS concerns gay men’s relationships with partners. Many participants emphasized that with so many anonymous and casual sexual encounters, many gay men have no information about their partners to give to the DIS. Others expressed concern about outing their partners or fear that their partners would find out that they were the ones who had given their names. Some expressed that divulging partners’ names felt like a betrayal. Others discussed how talking about sex partners forced some men to acknowledge that they are having sex with other men, which increased anxiety around PS. Lack of trust in government, which is often prevalent among gay men and especially men of color, was another barrier to PS discussed in the groups. A government employee knocking on one’s door was said to mean trouble to many people, and many would be suspicious or even angry about being tracked down and contacted with no warning. One participant pointed out that under these circumstances, many would lie to the DIS. Two others spoke of people who were afraid that they are being put on a government list and that the information may be used against them some day.

In almost every city, participants discussed that a major barrier to PS was people’s fear of having their confidentiality breached, which some said was inevitable when a DIS contacts a person at home or work. Neighbors, friends, family, colleagues, and partners were bound to find out that those being contacted had something that they did not want others to know about. This was said to be especially damaging for those on the “down low” who may have wives and children at home, for those in the closet who fear the stigma associated with being gay, or those in a steady relationship who do not want their partners to find out about their infidelities. As one participant posited, “When you’re talking about confidentiality, there’s always a breach, whether it’s in the hallway around other people or you come knocking at my door.” Another stated, “The stigma is attached to someone coming to the door. People know you got something”. Even receiving mail from the health department was cited by a participant as problematic, saying that, “If someone at your house goes through your mail and sees you have something from the health department, there’s nothing discrete about it.” Another participant spoke of the possible violence that could occur if a partner finds out that a person disclosed his name to the health department. Others commented on the shame that many feel if they have to talk to a stranger about behaviors that they may not feel comfortable with or about which they think they will be judged.

**Impressions and Experiences.** When asked if it was a good thing that sex partners of gay men testing positive for HIV be notified of their possible exposure, most of the men in all of the groups said that it was. Participants stressed that people had the right to know the information.
As one participant stated, “It wasn’t done for me, and I would never want to do it intentionally to someone else.” However, most also were critical of how PS are conducted. A wide range of opinions of the services surfaced during the discussions, ranging from very positive to very negative. These opinions were based both on the actual experiences the participants had with the services and on impressions they had drawn from conversations with others. Many of the positive comments about PS in general concerned the importance of trying to limit the spread of HIV. As one participant pointed out, “The information has to go out. The numbers are rising. By any means necessary, we have to put a lock on it somehow”. Another agreed saying, “What’s important is that preventive measures be taken because lives are at stake. It’s not just about me and my image. I need to get outside of it all being about me.” Others stressed the importance of helping people find out that they had HIV earlier in their infection so they could seek treatment and avoid getting sick. As one participant put it, “I know it’s better to know because there’s always something you can do to keep it from getting worse. If you don’t find out it can do a lot of damage to your body.”

In over half of the groups, participants discussed that it was helpful to have DIS notify their partners in situations where notifying them by oneself might be uncomfortable or even dangerous. One man stated, “if you don’t have the courage to tell them, it’s good that there’s someone that can do it for you”. Another pointed out that DIS can also help people to tell their partners through role-plays and coaching. Some participants especially stressed that PS were most effective when the DIS worked with clients as partners in the process of conducting notifications, allowing them to choose who they would notify personally and who the DIS would notify. Also, it was acknowledged that DIS often had methods of finding people that the clients did not know how to locate. DIS conducting testing in people’s homes was also highlighted as a helpful and discrete service.

Those participants who discussed having positive experiences with PS highlighted several factors that had worked well for them. One obvious factor concerned the way that DIS had treated them while providing the services, including being friendly, helpful, respectful, and compassionate and having the ability to generate trust. Two participants pointed out that they had appreciated the transparency the DIS expressed about the services, their purpose, how they would be carried out, and the fact that participation was voluntary. Participants especially appreciated the services when they were approached in a client-centered way. For some this meant that the DIS did not pressure them to talk about partners until they were ready. For others it was about the DIS discussing many of their needs with them and helping them access medical care and an array of other support services. One participant said, “I had a person that made me feel like it was all about me. It worked because he made me believe that everything was going to be better than okay.” Another said, “She gave me some numbers of places to contact like for CICP [Colorado Indigent Care Program] and to find insurance. She had a list of information she handed me that would help me feel more secure and comfortable with what was going on.” Some DIS were described as having gone “the extra mile” to help the participants get what they needed.

Unfortunately negative impressions and accounts of negative experiences with PS exceeded positive ones in the focus groups. These were said to have affected the amount and quality of the information gleaned from DIS interviews. Some impressions of and experiences with PS
involved people feeling as if they were being interrogated by the police, feeling aggressively harassed and threatened without being told the purpose of the services. One person stated, “In your mind, they [DIS] become part of the system. The system doesn’t always help. It punishes.” Others described the services as routine and impersonal, with DIS treating a very diverse set of clients with diverse needs in the same “one size fits all” way rather than being client-centered. One participant commented, “It’s made clear that DIS are not there for you.” Others commented on the lack of transparency about the services, with DIS failing to explain their purpose and that the services were voluntary. Several participants described the tone of the meetings as judgmental, others as cold and rote, saying that it seemed that DIS were reading from a list. One commented, “You can’t have somebody with a check list. Some people don’t show any feelings. Some people have monotones and you know it’s scripted.” Some DIS were described as coming across as disinterested and showing no compassion. One participant said, “They’re not in it to help me out, to make sure I’m getting the best medication. They’re in it to get paid.” Other DIS were described as too aggressive, which is reflected in the comment, “When people are coming to my door to tell me something, I don’t want them to be too aggressive. It makes me feel they’re trying to meet a quota. It makes me feel like I’m being used for them to do what they have to do.”

Many participants commented on the invasiveness of the questions asked as part of PS, with some describing them as humiliating and insulting. One said he thought, “I don’t know you, and you’re asking me all these personal questions’. … You feel like your privacy has been invaded.” Others spoke of the inherent assumptions and judgment of the questions, especially open-ended questions. One participant said, “You almost hear them say, what are you, a slut? Or a druggy? That’s what the questions imply.” Another spoke of friends who had been told that they were public health risks. “They start to feel like they’re a leper or are going to be prosecuted.” Other participants highlighted that some of the questions refer to activities such as drug use and prostitution that are against the law, and questioned why they would consider giving such potentially damaging information to a stranger. As one said, “…they ask me questions that could possibly land me in jail. I don’t know what they’re going to do with the information.”

Other comments concerned DIS acting unprofessionally. One participant said that the DIS patted him on the leg and kept calling him “sweetheart” which he found very offensive. Others spoke of instances in which DIS had discussed other people’s private information, including HIV status, in social settings. Another set of comments from participants focused on how DIS often do not understand the gay community and that anonymous sex is fairly common, making it difficult for clients to give partner contact information. One said, “I was giving my best effort. I didn’t need judgment. I’m trying to cooperate. Right, wrong, or indifferent, the gay community is what it is.” Participants who discussed instances in which DIS acted inappropriately said they had no idea how to report those instances to the health departments.

Two topics that were widely discussed by participants in all of the cities concerned the means of contact used for PS and their impact on client confidentiality. There were a variety of opinions expressed by the participants about the means of contact. Some were furious that someone left letters on their door, and a few complained about letters that were sent through the mail. Many participants admitted to not responding to phone calls because they did not recognize numbers on
caller IDs or because they did not know what it was about. Some mentioned problems with DIS refusing to give information over the phone, making people concerned about what the DIS were calling about but having to wait to find out. As mentioned above, many had problems with people showing up at their door unannounced, especially if it was obvious to onlookers that the DIS were from the health department and thus raising their suspicions.

One of the most impassioned topics discussed by the focus groups concerned the timing of PS. Although a few participants expressed that they were not bothered about having to talk to DIS about sex partners right after receiving their HIV diagnosis, most thought that they were not ready for the conversation at a time when they were experiencing so much emotional turmoil. Several mentioned not being able to listen or think clearly, and therefore could not provide good information. Some stressed that the conversation with the DIS so soon after hearing their HIV positive diagnosis had seriously exacerbated their emotional distress. One participant commented, “When I tested positive, I was in shock. I could hear her asking all these questions, but I was freaking out and in disbelief.” Another said, “I needed to have time to myself… I needed to get it into my mind that I was okay.” A third stressed that, “A lot of people’s brains will just shut down. I just wanted to crawl in a corner and hide for a few days.” Many emphasized how people at that point need to have someone talking to them about how they are going to deal with HIV and get the medical and other services and support that they need before expecting them to discuss partners and notification. One participant articulated it well in saying, “You have to be at a point where you’re comfortable with your levels and your health. In that first instance, you’re going to be angry, and it’s only going to get worse. When you first find out, they should focus on you getting healthy and getting your head together.”

**Partner Services: Suggestions for Success**

A very large number of suggestions for ensuring the effectiveness and appropriateness of PS were offered by the participants in this formative evaluation. Although they do not fit cleanly into distinct categories, they are somewhat loosely grouped below.

**Comprehensive and Client-Centered.** First, many people discussed the need for PS to be highly integrated into a comprehensive approach to offering services to those who are newly diagnosed with HIV and other STDs and to their sexual partners. Such an approach needed to be client-centered, or highly tailored to the needs of each individual. This would first entail having discussions with clients, offering assurance that they can get help and giving them the opportunity to express their concerns and get their questions answered. It would then involve assuring that HIV-positive clients are linked to medical care and to related services based on clients’ needs. These could include services such as: 1) poverty-related services such as income assistance or housing assistance; 2) mental health services and support groups; 3) substance abuse treatment; and 4) linkage to support organizations. It would also include linking identified sex and needle-sharing partners to HIV and STD testing, prevention services and materials, and other needed services. As one participant asserted, “There needs to be a link between PS and Linkage to Care so you can automatically get people linked to services and started on treatment. There are still people today who don’t know how to get linked to services.” Another stated, “It has to be the full package. It’s got to be more than getting tested and giving the information.
Give information on available support groups….Link people to organizations. Assure people that this is their chance to live a long and healthy life.”

Additionally, a comprehensive approach would include providing people with the information that they indicate they need, including information about: HIV and other STDs; what they can expect if they are HIV positive in terms of disease progression; the types of medications available; the importance of adherence to medications; the definition and role of viral suppression in prevention; available resources; how to access services; how and when to disclose positive HIV status; and how to keep sex partners safe. The importance of information was stressed by one man who said, “If the prevention team isn’t prepared to answer questions, they don’t know what to tell you to do next.” It was also said to be critical that people be treated as individuals and not subject to a “cookie cutter” approach meant for everyone or dealt with based on assumptions and stereotypes.

**Timing.** Another set of suggestions for improving PS concerned the timing of the services being offered. Although many participants saw the need for such services, only two expressed that they should be offered at the time people are first diagnosed with HIV. The vast majority of the participants discussing the subject thought that they should be offered later, although the time people thought they should be offered varied. As one participant stated, “You’re never ready for that curve ball, so you don’t need more things to catch you off guard.” Most expressed that DIS should wait until people are ready to talk about such sensitive information, with many agreeing that it was important for clients to feel that their needs are taken care of before partner elicitation is broached. As one expressed, “When those things are taken care of, that’s the point when you can start asking about partners. You telling about your partners is not going to take away from your health. You going out to get medicine, that’s where time is precious.” Another stated, “As soon as you find out, you’re going through all this shit. You want to focus on getting yourself together and seeing what you do know. So much goes through your head. When you’re at a point when you can handle the questions, that’s when you should do it.” A third commented, “First we need to know what we need to do for ourselves and then you can gain the trust. It’s still implemented, but changed around from where it’s implemented now.” More specific suggestions about when the services should be offered ranged from a few days after receiving a diagnosis to a month later.

**Means of Contact.** Although many of the participants complained about the means of contacting clients typically used by DIS, there was no consensus about how it should be done given that everyone is different. Many agreed, however, that just showing up unannounced at people’s homes or workplaces and leaving notes on doors were not appropriate and often compromised people’s privacy. Letters sent through the mail were mentioned as preferable most often followed by phone calls. One suggested using a trusted third party (someone respected in the community). Many participants suggested that getting information from people about how they preferred to be contacted before the contact was made was the best solution. This information could be elicited from the person giving positive test results or by asking positive clients about the best ways to reach their partners. One person suggested that he would have preferred someone giving him a phone number to call where he could leave his partners’ contact information on a voicemail and not have to talk to anyone. Another empathized with DIS, knowing that many people often do not respond to their phone calls. A third expressed concern
for ensuring the safety of DIS when contacting people. A fourth stressed the importance of DIS trying multiple ways to contact people and being persistent. Several participants stressed the importance of DIS partnering with those testing positive for HIV and other STDs in the notification of partners, with the clients themselves doing the notification whenever possible.

Several participants suggested trying to make an initial contact with people over the Internet, especially when notifying partners. Some stressed the importance of limiting the information to appeals for the person to call the DIS or come to the health department. Others suggested giving information that the person could possibly have been exposed to something without being specific as to the particular disease. One person promoted the use of Internet partner notification sites saying, “They have services now that when you find out you’re positive, you can send an anonymous e-mail….You don’t sign it….They can’t track it. Sometimes that’s easier on certain people.” Another thought the Internet could be used to pass on information to the health department. He said, “There should be somewhere on line that you could tell the health department anonymously that they need to let someone know they’ve been exposed. If it’s simple and I can type it right there, it could work. If it’s not simple, you might not.”

Most importantly, participants in all of the groups stressed that whatever the means of contacting those recently diagnosed with HIV and other STDs and their sex partners, protecting confidentiality was critical.

The Role of Peers. Another topic of discussion about PS concerned the importance of people being contacted by those they are most likely to consider their peers. Matching DIS to clients based on factors such as age, gender, ethnicity, and sexual orientation was said by some to improve communication and comfort levels. As one participant expressed, “If you come to me to say I’ve been exposed, it needs to be somebody that I consider a peer….Otherwise, if you were knocking on my door wanting to know who my partners are, I would think you were Gestapo or something, and I wouldn’t be able to relate.” Another said, “….a lot of gay men are not going to open up to some woman knocking at the door. [It would be better] if there was a peer or someone you could identify with.” A third stressed, “The majority of health department staff should be gay because gays are the most impacted by HIV.”

One of the most impassioned parts of the focus group discussions concerned the importance of clients being contacted by people who are living with HIV. Participants discussed how critical it can be for someone who is newly diagnosed with HIV to be able to hear about the experiences of those who had been living with HIV for a long time so that they can know more about what to expect and what resources are available. One participant reflected back on his diagnosis saying, “What was important for me was that one of the first people I talked to was HIV positive. I was breaking down, and he disclosed to me. That was the moment that changed everything for me. It made everything after that so much easier.” According to the participants, an HIV positive DIS can better relate to a client’s angst about learning they are positive and about participating in PS since they had similar experiences in the past. One participant articulated this saying, “That person can give a whole lot better message…. They can say ‘I was diagnosed five years ago, and this is what I’m doing.’ He’d probably get a hell of a lot more information…. He can say, ‘I know what this is like. Let’s figure out what we can do to go forward.’” Another stressed that HIV positive DIS are likely to be more compassionate saying that, “Compassion is going to come from employing people who know what it’s like to have been put in that position. It
doesn’t mean all DIS have to be positive, but who better to know what it’s like to get that news than a person who has gotten that news.”

Others talked about the benefits of having HIV positive people on staff, whether as DIS or in an auxiliary role for these same reasons. One participant commented, “By far the most important thing for me was talking to people who had been living with it. I don’t know how you could integrate that into PS, but there’s no question that there is no staff member at any organization anywhere who’s negative that can make half the difference as somebody who has been living with it.” Many emphasized that people living with HIV needed to be in paid positions rather than used as volunteers, with many discussing important work that they had done in the past, but had never been paid for it. As one participant emphasized, “We are the best people for the job, but it’s not us that gets the job.” Another pointed out, “We receive benefits from you, but we can’t be employed by you.”

A third role in PS for HIV positive people that was discussed in the focus groups concerned them acting as advisors to health departments on how PS should look and be conducted. One participant said, “We should have a forum for gay men to talk to the health department about PS….It would be like them going to ‘gay class’ or just gathering data for PS to go back and decide on strategies they can implement. Let gay positive men share their experiences.” Participants also stressed the importance of having HIV-positive gay men be involved in the training of DIS. Participants in all of the focus groups responded positively when asked if they would participate in such an advisory capacity and in the training of DIS.

Other Suggestions. Finally, several other suggestions for PS were made by a small number of the participants. One concerned the importance of bringing discussions of treatment and suppressed viral load into the discussions that DIS have with clients, and, more generally, into discussions about the way PS should be implemented. One participant articulated this well in saying, “That’s a conversation that men are going to be having a lot. But that’s not a conversation that DIS are having with people. From a larger public health perspective, what does it all mean that people are taking these medications and viral load is zero and the evidence is suggesting that transmission is low? Would it be helpful to have that as a prevention topic?” Another set of suggestions concerned the importance of evaluating DIS in an effort to “weed out” those who are the least effective. As one person put it, “There’s some people that hate their jobs and are doing it for the paycheck, and they’re not held accountable. Those people need to be booted out of the system. You need to get people who actually care in those positions.” A third set of suggestions focused on the importance of doctors and other providers letting their clients know about PS before they are contacted by DIS, so that they would not be caught off guard and would know what to expect. They stressed that clients would be more likely to respond and participate in PS.
**Disease Intervention Specialists: Suggestions for Success**

Many suggestions were also offered by the participants concerning the type of people that should provide PS, the training and knowledge they should have, and how they should approach the job. Some information in this section is reflective of and similar to the information in the previous section, but more focused on the DIS themselves.

**Character.** One set of suggestions concerned the ideal character of PS providers. As would be expected, the two suggestions offered most by the participants were that DIS needed to be compassionate and non-judgmental. Participants stressed how important it was for DIS to try to empathize as best they could with the people they are contacting, trying to understand what people are going through and trying to put themselves “in the clients’ shoes”. They need to be someone who expresses genuine concern for people and their situations. As one participant stated, “You have to have somebody who really cares about people.” Another said, “The most important thing for DIS is to be sensitive. They need to think how they would feel if they were in the same situation.” Some pointed out that DIS can often start out being compassionate, but lose that compassion over time after talking to so many clients. One person expressed, “They need to approach me and remember how it was when they started the job and what their job is really about.” Also, given that DIS are dealing with highly sensitive issues concerning people’s private lives, it is critical that DIS recognize and deal with their own biases, or otherwise risk doing harm to someone who perceives that they are being judged. Clients must feel free to talk about their sex lives and other related personal matters for PS to be effective. One participant described it well saying, “The person doing the job needs to step back from the situation and accept that anything’s possible. If you take that attitude, then you can talk to anybody. If people pick up that you’re judging …they’ll shut down. And it can be something as small as a facial expression. A lot of people are narrow-minded, and they project it and people pick up on it.” Another participant who felt judged when he was interviewed by a DIS had this insight. “I’ve just been told I’m positive and now I have a person sitting in judgment of me. Why should I cooperate? You’re in a fragile state, and it can be something as simple as a look.” Other characteristics that some participants thought necessary in a DIS included patience, professionalism, and persistence.

**Knowledge.** Learning to become a good DIS takes a lot of time, and there are many types of knowledge and skills that a DIS needs to master to be effective and appropriate when conducting the job. Participants said that DIS need to always ask clients what questions they have and be able to answer them. First, participants stressed that DIS needed to have extensive knowledge about the diseases they are discussing with clients. They emphasized that people need to know what they are dealing with and what to expect from the disease. One participant admitted, “I expect a lot out of DIS. They need to have a great understanding of HIV, the latest research, the medications that are out there, and the side effects.” Another said, “They need to be up on the information, the statistics.” It was also stressed that it was important that DIS assess clients’ level of knowledge, which could range from only very basic knowledge about sex and sexual health to a relatively high level of expertise about HIV and other STDs. Second, participants thought it important for DIS to have an extensive grasp of available resources and knowledge of what clients need to do to access those resources. One participant adamantly expressed, “They [clients] need to know what’s next. You need to have a plan in place. You need to have the
referrals ready. You need to assure them that you have their best interest in mind..... You let people know what it’s going to look like, what they need to do, when labs get done, etc. Introduce them to the people and the system. People are always going to want to know ‘now what?’. They need to know exactly what is next and what they need to do.”

A third type of suggested knowledge that a DIS needed most based on the participants feedback was knowledge of the communities people are part of and the social context of people’s lives including basic norms, types and extent of diversity, and the social determinants of people’s health. One participant emphasized, “[You need to know the] socioeconomics of the people you’re going to be seeing. You need to understand the issues of that community.” Another said, “Get in there. Find out how they struggle, how they function.” Knowing about people’s communities, especially the gay community, was said to be critical to DIS if they are going to know how to help people and how to avoid being judgmental, particularly when it came to sexual behaviors. One participant put it simply saying, “The right language creates an understanding that generates rapport. You need to represent an understanding of the world people are living in and that it’s OK to disclose what I’m doing.” Another elaborated further. “You need to acknowledge that you know how things are happening. It can be very simple. You can create a foundation where it’s OK to disclose that you had five tricks last week, but I don’t know all of their names. If you create that from the start, the interview will go a lot better.

Asking questions that reveal that you know the scene that people may be operating in and give them options….We’ve all seen situations where people asked a question the wrong way and it all went wrong.”

Although some participants wanted DIS to realize that gay men are “just regular people, no different than anyone else”, others emphasized the need to understand the diversity in the gay community or understand the overlapping communities of which gay men are a part. As one man said, “If we’re dealing with the Black MSM community, masculinity is huge, especially guys on the down low. If the interview tactics used by the DIS makes you feel less than a man, it’s going to turn him off real quick, and he won’t talk to you. Whether it’s a drag queen or a meth user, you have to adapt the tactics to the demographic. It’s important to know the nuances of all of the different groups.” Another person mentioned the importance of DIS being seen out in the community and becoming more familiar with it firsthand while the people in those communities become more familiar with the DIS. He stated, “It needs to be a familiar face versus someone just popping up that you don’t know and you don’t know that they care”. Others did not necessarily agree with this, saying it could cause confidentiality issues when known DIS are seen talking to people.

**Generate Trust/Build Rapport.** One topic emphasized by the focus group participants concerning the relationship between DIS and clients was the importance of the DIS taking the time to build rapport and generate trust with clients before discussing sex partners. Participants stressed that a DIS needed to first spend time getting to know a client, discussing client concerns, and answering their questions. DIS needed to let clients know that their needs were a priority, and make resources available to them. One participant said, “I feel like if there were resources extended...instead of seeing someone you see once that just wants a lot of information, and they’re not connecting with you as a person. You feel like they’re asking about everybody else. You wonder ‘what about me?’.” Another stressed, “It’s about having a conversation rather than
asking questions. It makes them feel more comfortable. Tell them that you know they have a lot of stuff going on, and you’re there to help.” One participant laid out the initial process this way. “First introduce yourself and relax a while and not just dive into the questions. Develop rapport, and show your compassion. One of the main things when you first meet is to shake hands and show you’re not afraid to touch them. You’re still a human being. You’re still a person….You have to have rapport for someone to get comfortable with a person. It might be a thing where you go to meet them one time and ask, ‘when can I come back and talk to you?’ Go two or three times so you have a familiarity with that person. They almost become your friend then.” Another added, “If you feel like you’ve got a DIS that you can call and talk to and don’t feel judged, you will give more information to them.”

Participants also emphasized that DIS needed to be upfront about PS and what the services entail beforehand, and they needed to acknowledge that the process and the subject matter can be difficult for many people. As mentioned above, participants appreciated DIS who explained the reasons for PS, how the information gained from the interviews would be used, and who would have access to the information. One participant said, “Stress that you want to get to know the person and you’re not judging them. Acknowledge that you know the questions are personal.” Another added, “Make it very clear that the situation is going to be difficult and there’s a lot to discuss. Explain why talking about partners is very important.” A third stressed, “You need to explain to the person that there could possibly be some loss. Depending on your situation, it could be dangerous. You need to let them make the choice. They don’t ever talk about the downside and possible risks of PS.”

**Client-Centered.** It is important to stress that even though participants in the focus groups emphasized that DIS needed to understand people’s communities, they also needed to be aware of succumbing to stereotypes about those communities. Participants advised that those training DIS needed to address those stereotypes. Communities are all obviously highly diverse, and individuals normally belong to many communities and are guided by multiple sets of norms. As one participant said, “Gay men come from many different backgrounds, and none of them are that much alike. They’re just as diverse as the community at large. Many people make assumptions that we are very similar, but that’s not the case.” Furthermore, every individual’s situation and specific needs are different, and, therefore, DIS must approach each person as such. As one participant stated, “…they’ve approached so many people that they’ve got a frame of mind that it’s going to be this way. That’s how it is. Everybody’s different. It affects their approach looking at everybody the same….This person, once you finish with him, you need to deal with the next person like it’s the first person you ever sat down with and talked to.” Another agreed saying, “The public health workers see a lot of people, and after you deal with so many people it becomes general….But each person is different, and you need to deal with them as such, like it’s the first time they’re actually hearing it, because it is.”

Participants also stressed that DIS should not pressure clients to participate in PS until they are ready. As one stated, “You should talk to the person and feel them out a little bit. If they’re scared to death that the world’s going to end tomorrow, then I wouldn’t hit them up with those questions. I would do a follow-up within a day or two. Let them calm down first, and let them process it. Once that’s accomplished, you can move to those questions.” Another added, “You don’t want people to wait, but if you push them before they’re ready, they’re not going to do it at
all.” Participants especially emphasized that if a client is expressing critical needs when a contact is made, the DIS should make sure that the client is linked to appropriate services immediately. As one participant said, “If they have more issues and more anxiety, they need to quickly link people to a case worker that you can collaborate with.”

**Protect Confidentiality.** A final set of suggestions that the men in the focus groups had for DIS, is that they have the skills and approach their work in a way that ensures that people’s confidentiality will not be breached. As mentioned in the above section on “Means of Contact”, showing up at people’s homes or work places unannounced, leaving notes on people’s doors, or arriving at people’s homes in marked health department vehicles or wearing badges were all ways that would raise the suspicions of anyone that is around, including neighbors, coworkers, family, partners, and friends. Contacting people through the mail or by phone and then setting appointments to talk to people in the places of their choosing was said to be much more acceptable. One participant stressed the importance of DIS knowing the city well enough to be able to make suggestions of “good confidential places to meet without people being able to hear. You don’t want to sit in the Starbucks.” As mentioned above, participants also stressed the importance of DIS explaining to clients about how their confidentiality would be protected and how the information would be used.

**Other Needs**

The focus group discussions all ended with the facilitator asking the men’s opinions about improving HIV testing among gay men and other MSM and also about what else needs to be made available for their populations in these cities. The information provided on these subjects by the participants was extensive and is summarized in the bullet points below.

**Improving HIV Testing Among MSM**

- Offer testing in clubs, balls, baths.
- Emphasize the importance of early detection of HIV infections; encourage people to know their status; let people know that they will not always show symptoms if they’re positive; put testing in a good light.
- Offer and advertise testing in many community venues frequented by MSM and others at higher risk such as malls, grocery stores, pharmacies, adult entertainment stores, Pride events, thrift stores, homeless shelters, etc.; make testing available any day and time.
- Advertise about the importance of testing and about where testing is available; use media such as TV, billboards, gay newspapers, posters, and flyers at concerts and other events.
- For those using home HIV tests, find ways to encourage them to seek help immediately if they test positive including making a list of local resources available with the kits.
- Encourage high school students to get HIV tests while they are still covered by their parents’ insurance.
- Try to make frequent testing a norm so that people are more relaxed about testing.
- Hold city and statewide campaigns to promote testing; hold testing drives.
- Make information about HIV more available through the media; include information on the statistics and local resources; help to overcome the stigma.
- Make testing more readily available to everyone.
• Make HIV testing mandatory.
• Offer incentives to encourage people to test for HIV and other STDs, including discounts on admission to certain venues.
• Include HIV testing in physicals for youth and adults.
• Make efforts to cut down wait times for testing at clinics.
• Provide testing in more places that are smaller and more private than clinics.
• Provide testing in a mobile van that travels to different parts of the city; offer other outreach testing.
• Do not nag people who do not want to test.
• Ensure that people know how the test works and that they understand the window period.

Meeting Other Needs of MSM

• Information
  o Provide retreats where men can get information about prevention and care.
  o Provide men with information on safer sex alternatives other than male condoms; include information about the use of female condoms for receptive partners; show people how to be safer and still enjoy themselves.
  o Provide information on related diseases such as HPV and hepatitis and their consequences; encourage men to get available vaccinations.
  o Integrate the distribution of information into larger events, such as including one-minute spots at drag shows or other events.
  o Use available data to inform prevention.
  o Distribute information and condoms through outreach; distribute information on available resources; distribute information on what agencies have to offer.
  o Develop opportunities for gay men in communities to have group conversations about community issues and share information.
  o Provide information on HIV to the general public to help alleviate stigma
  o Provide people with better information about post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP).
  o Ensure men know how to use condoms correctly.
  o Start sex education in schools early, such as in 7th grade; encourage parents to talk to their children.
  o Make sex education classes longer, such as a whole semester.
  o Do more outreach using peers to reach out to their communities.
  o Conduct outreach to those with no jobs or health insurance; place written information in venues where they tend to congregate.
  o Concentrate on getting information to those who are HIV negative.
  o Get basic information out to those who need it through events and workshops that are fun.
  o Have people living with HIV give information to others and promote prevention.
  o Ensure that people understand that HIV is not a “death sentence”.
  o People should educate themselves so that they can educate others.
  o Educate people living with HIV (PLWH) about the care systems and how to utilize those systems.
  o Provide HIV education in correctional facilities.
Provide information to PLWH about the meaning of viral suppression.

- Provide linkage to other services
  - Ensure that you can link people right away to needed medical and other services; ensure that you can connect people to resources immediately when needed.
  - Let PLWH know where to access healthy foods.
  - Link drug users to harm reduction programs.
  - Make annual physicals available to everyone.
  - Ensure that those who are newly diagnosed with HIV know what they need to do and the specifics of how to access services; help people with the care system and cutting through “red tape”.
  - Link people to counseling; address mental health needs.
  - Make more support groups available led by counselors; offer more opportunities for PLWH to talk to each other.
  - Link people to gay or gay friendly providers.
  - Ensure that PLWH are receiving anti-retroviral medications.
  - Link people to buddy systems for mutual support.
  - Link heterosexuals living with HIV to groups to gain mutual support and deal with issues particular to their populations.
  - Link people to prevention groups for positives and negatives.
  - Link people to more opportunities for people to socialize.

- Provide programming
  - Provide more creative programming for youth.
  - Encourage youth to buy into prevention from an early age; get more young people involved in prevention.
  - Provide groups that are only for youth.
  - Involve PLWH in prevention programming.
  - Integrate programs about HIV with other topics; provide more “one-stop shopping” for needed services; address multiple needs.
  - Provide more programming for people who are HIV negative.
  - Provide programming tailored to specific populations.
  - Get leaders from different populations to buy into what you are doing and then encourage others to participate.
  - Get PLWH out into communities to talk to people, give condoms, do condom demonstrations, talk about diseases, etc.; talk to people who are getting high.

- Community involvement
  - Get input from community members on public information campaigns on what is most likely to grab their attention.
  - Ensure that agencies and businesses are more responsible to the community.
  - Gay men should be taking care of their own communities as they did during the early years of the HIV epidemic.
  - Health departments should engage gay men in more forums and discussions and then heed their suggestions.
Include a diverse group of gay men in those discussions and in program planning; include young gay men.

Secure funding for grassroots prevention.

Have community organizers teaching gay men about their history and the history of HIV; encourage gay men to advocate for themselves.

Make it more financially feasible for gay men to get involved; provide jobs for gay men in STD/HIV prevention.

Include images of people from communities in literature that is distributed.

Have more gay men living with HIV conducting outreach.

Mental health in the community should be addressed by community members.

Findings and Implications for Partner Services

This formative evaluation revealed that most participants were supportive of efforts to ensure that sex partners are made aware of potential exposures to HIV and other STDs. Despite generally supporting the notification of partners, there seemed little evidence of messages coming from within the gay community that reflected this level of support or encouraged men to participate in activities to ensure that partners are notified. Additionally, while participants were generally supportive of partners being notified, they expressed concerns about the manner in which this is or would be done.

Many of the participants were familiar with PS and reported past experiences with this intervention. Despite such experiences, they often seemed less familiar with the term "Partner Services" and often referred to PS-related activities by other names. For many of those familiar with PS, they were unaware of PS until after they were contacted by a DIS following a positive test or notified as an exposed partner. A few participants reported that their care provider had informed them that they would be contacted by the health department. A number of participants reported that they were unaware of PS prior to hearing the intervention described during the focus groups.

Some participants described positive experiences in which a DIS was supportive, referred them to needed services, assisted them in notifying partners, and otherwise helped them get through a difficult time. Still others described experiences that seemed inconsistent with standard practice for conducting PS (e.g., DIS flashing a badge, loudly announcing that they were from the health department, talking openly about a person's HIV status in public spaces or with people not authorized to have such information, or otherwise treating people disrespectfully). When relating negative experiences, few participants indicated that they knew about or had accessed official mechanisms for reporting these experiences or having their complaints and concerns addressed.

In general, the focus groups revealed that few participants were knowledgeable about PS protocols and procedures and unaware that professional standards for the delivery of PS exist. The general lack of information about the existence of PS, standards and procedures for PS delivery, and mechanisms for reporting substandard PS practices likely results in misinformation and contributes to resistance to this intervention among many MSM.
Participants had wide ranges of opinion regarding standard DIS practices including the use of open-ended questions, best times to offer PS, who should be involved in PS delivery, and methods for contacting people at home or at work. However, there seemed general agreement that PS should be conducted compassionately and that DIS should demonstrate a general concern for the health and welfare of the person living with HIV as a priority.

Participants offered a number of suggestions for improving and ensuring successful PS outcomes and expressed their belief that gay men should be involved in reviewing and revising PS activities. Many participants stated that they themselves would participate in these planning activities if given the chance to do so.

Participants raised many of the same issues and expressed many of the same sentiments related to PS regardless of the city in which they lived. However, there were some issues that seemed unique to certain cities (e.g., the existence of balls as a social venue, the degree to which gay men are open about living with HIV, the amount of discussion about the implications of undetectable viral loads). Such differences suggest that a single approach for improving PS will not address issues that are unique to certain cities. Instead, various PS improvement strategies and initiatives will likely need to be undertaken that reflect the unique patterns of circumstances that influence the acceptance of PS and other HIV/STD prevention initiatives.

**Recommendations**

The following recommendations are proposed in light of the information shared by the project participants, their suggestions for improving PS, and the authors’ experiences providing PS in Colorado and their knowledge of many components of PS programs and related PS practices. The recommendations loosely fall into two categories related to the restructuring of PS and the training of DIS. Most of the recommendations require greater action at the level of state and local health departments involved in the delivery of PS. However, the MAPTC can support these programs in their roles as curricula developers, trainers, and champions/disseminators of best practices.

**Restructuring of Partner Services**

1. *Assess and address the needs of the person newly diagnosed with HIV as a priority.* Participants reported being unable to engage in a discussion about partners when their concerns had not been addressed. In fact, what was perceived as an undue focus on partners influenced some men to resist such discussions and perhaps resulted in lost opportunities when men who otherwise might have provided useful partner information were experiencing disorientation and emotional trauma. Therefore, PS should be closely integrated with linkage to care and other services. Place the initial priority on meeting the needs of the people testing positive for HIV or other STDs in a comprehensive and client-centered manner. Time the implementation of partner elicitation based on an assessment of the clients’ readiness. Accordingly, adjust the required timeframes related to the completion of interviews and case closures.
2. **Ensure that clients know that they will be contacted by PS providers before the contact is made.** Partner with providers, especially those delivering HIV and other STD test results, to ensure that they give clients this information. Ensure buy-in from those providers as to the value of such services, and provide them with sufficient information about the services so they can share that information with clients before those contacts are made. Develop procedures through which providers get information from clients on how they prefer that those contacts be made.

3. **Advocate for changes to state laws surrounding non-disclosure.** Reassess any agency procedures that are or may be perceived as punitive, and utilize punitive measures only as a last resort. Participants discussed the impact of state laws and punitive measures on the part of health department staff as, in many cases, being counter-productive, making some people less likely to test for HIV or discuss their behaviors openly with DIS. Additionally, consider issues related to suppressed viral load in making determinations about clients who may be considered as public health threats.

4. **Recruit gay men living with HIV to work as DIS or to work alongside DIS when clients’ needs are assessed, when partners are elicited, and during the partner notification process.** Many participants discussed the importance of being able to talk to someone else who is living with HIV, especially when they are first diagnosed. The potential for HIV positive staff expressing genuine empathy, discussing difficult topics, and gaining better information on partners from clients was said to be much greater.

5. **Enhance community support for notifying partners of possible exposures to STD/HIV.** Despite many participants voicing their support for the idea of notifying partners of a potential exposure to HIV/STD, there were few who reported hearing messages from within the gay community that this was a desirable practice or community norm. Making men aware of the existing levels of support for partner notification and linking this support to PS as a viable, accepted partner notification tool might make it less likely that PS-related activities are viewed as being imposed by others outside the gay community with agendas and priorities inconsistent with those of gay men. Such efforts would include working with organizations and individuals respected by gay men to develop and disseminate messages supporting partner notification and encouraging men to work with PS providers to ensure that their partners are notified.

6. **Brand and market PS activities.** Many participants did not know that they would be contacted by a DIS until after they had a positive test. Also, there seemed to be a great deal of misinformation about what one should experience when offered PS. Disseminating information about PS might lessen suspicion about the service as well as give men a sense of agency as they learn about the process, their rights related to receiving the services, safeguards to protect their confidentiality, advantages and disadvantages of certain PS approaches, and the role(s) they might play in helping ensure that a partner is made aware of an exposure and the need to seek appropriate follow-up.

7. **Develop and advertise mechanisms for men to report substandard or unprofessional PS delivery.** Participants reported instances when they felt disrespected or observed a DIS talking to an unauthorized person about someone’s HIV status. They did not indicate that they were aware of ways to have such issues addressed. A system to follow-up with complaints will likely help build support for PS among gay men. Information about ways to report poor DIS performance or dissatisfaction with PS should be provided to all original patients, partners, suspects, and associates.
8. Implement mechanisms to ensure the delivery of quality PS. In addition to ensuring that MSM receiving PS are aware of how they can report substandard service delivery, PS programs should implement quality assurance mechanisms for assuring courteous and respectful DIS performance that are not solely driven by consumer complaints. For example, supervisory staff should regularly observe DIS conducting interviews and partner investigations and assess their performance against recommended performance standards.

9. Review and revise training curricula, exercises, and materials to ensure respectful and compassionate PS delivery by DIS. Many participants expressed dissatisfaction with the use of open-ended questions. Participants did not know the rationale for questions that they described as accusing them of behaviors in which they had not participated or that seemed to stereotype all gay men. More time discussing the rationale for using open-ended questions at the beginning of an interview might lessen discomfort with this investigation technique.

10. Review PS protocols and procedures. While many participants agreed that partners should be notified of an exposure to HIV/STD, most expressed concerns about the process by which this is accomplished. Information from the focus group and interview discussions suggest a wide range of areas that might be explored to identify more optimal PS outcomes and/or other public health benefits including assessing the needs of the person with HIV/STD, making appropriate medical and other referrals, identifying the most appropriate times to offer PS, identifying acceptable mechanisms for contacting partners and persons in need of an interview, use of open-ended questions, involving PLWH in the PS process, and providing information about the implications of undetectable viral loads on decisions regarding sexual practices and infectiousness.

11. Local jurisdictions and the MAPTC should develop and implement plans for ensuring the meaningful involvement of MSM in developing quality PS programs including addressing all of the recommendations found in this report. They should involve MSM in defining “success” in terms of what successful interactions with clients would look like as well as successful outcomes of those interactions. Participants widely agreed that gay men should be involved in reviewing and developing PS programs and many stated that they would participate in such planning activities. The focus group discussions suggest that there would likely be a wide range of opinion regarding appropriate PS priorities, protocols, and practices. Differences in environmental contexts across the six participating sites suggest that a one-size-fits-all approach to PS delivery may meet with only limited success. Involving local men in developing PS plans might help bring about improved PS outcomes that reflect being mindful of and responsive to these differences of opinion and context. It may prove to be the case that men choose to make few changes to PS programs as a result of their involvement in a PS review and planning process after they are engaged in identifying desired outcomes, learning the rationale underlying current PS practices, and considering other alternative practices. However, the resulting programs will likely have increased support through the acknowledgement that they were developed as a result of a partnership between local communities and their respective health departments.
Training of DIS

12. Complement trainings such as Passport to PS with instituted conversations with groups of gay men who have received PS in the past. Incorporate role plays with gay men living with HIV into trainings.
13. Require the reading of this report for all DIS to help them gain perspective on people’s experiences with the services and on how clients want the services to be implemented.
14. Review and revise trainings to ensure respectful and compassionate delivery of PS by DIS.
15. Provide in-services to DIS on an on-going basis and require ongoing study to ensure that they have thorough and up-to-date information about various aspects of HIV and other STDs and about resources that they can share with clients.
16. Train DIS to provide linkage to care and other related services or incorporate mechanisms through which they work closely and in a highly integrated way with those who provide such linkage.
17. Train DIS in the provision of comprehensive and client-centered services.
18. Encourage face-to-face discussions with clients, and train DIS to cover necessary information in a conversational manner rather than through the use of a checklist. Train DIS to discuss the purpose of PS and to assess client readiness before beginning the partner elicitation process.
19. Ensure that DIS understand the nuances of protecting confidentiality. Consider other options than requiring or encouraging them to show up unannounced to people’s homes and workplaces in search of HIV positive clients or their partners or to leave notes on doors. Ensure that they do not utilize health department vehicles that are marked when working in the field or easily visible identification.
20. Ensure that DIS understand how the Internet has influenced MSM patterns of socializing and finding sexual partners. Train them to use the Internet and other electronic media to conduct HIV/STD prevention activities.
21. Train DIS to assist MSM in making healthy choices in the age of antiretroviral medications and undetectable viral loads.

Limitations

As with many qualitative projects, this report does not capture or represent the thoughts of all gay men and other MSM but only highlights key themes that arose among groups of MSM in six larger metropolitan areas located in the central U.S. The short timeframe by which the project needed to be completed required that the MAPTC rely on the connections and relationships of partners from state and local health departments, AIDS service organizations (ASO) and other community-based organizations (CBO) serving gay men and other MSM in those cities. The original intent of the project was to bring groups of men to the table that had experienced PS within the previous five years and who represented the current epidemic in each of those cities in terms of age and ethnicity. The agency partners in each city were extremely helpful and effective at bringing diverse groups of men to the table, and most reached out to other agencies, with varying degrees of success, to ensure good representation in the groups. However, as with
any focus group, participation is restricted not only by those involved in the recruitment and those invited to the table, but ultimately by those who are willing to come to the table. As a result, in most of the cities, the ethnic and age breakdowns of the participants did not accurately represent the local epidemic. Additionally, the demographic forms filled out by the participants did not ask for information about the last time they had an experience with PS, which would have been helpful. It was clear from discussions in the groups that some of the participants had been diagnosed with HIV many years prior and possibly were less able to comment on the way PS are currently implemented. However, all of the participants were able to discuss how those services should be implemented and what they should involve.

Also, given that most of the participants were recruited by staff at ASOs and CBOs serving men living with HIV, it is not unreasonable to believe that participants’ responses may more accurately reflect those of men who are receiving HIV/AIDS-related services as opposed to men who do not receive such services. Furthermore, early in the recruitment process, an ASO recruiter suggested that potential participants might be reluctant to reveal their HIV status if living with HIV. In response to this concern, many men were invited to participate if they had been diagnosed with an STD/HIV and subsequently received PS, had been contacted after being named as a sexual or needle-sharing partner, or otherwise had opinions about how PS should be conducted when delivered to MSM. Participants were not asked their HIV status as a condition of participation but all were expected to be MSM as described in recruitment materials (e.g., flyers and project descriptions). Opinions offered by participants should therefore not be attributed solely to men living with HIV; however, it was clear from the discussions that most of the participants did draw from their experiences with public health after receiving an HIV diagnosis. Given that the majority of participants were likely men living with HIV, their perspectives and recommendations regarding PS may differ significantly from men who are at risk but who have not received an HIV diagnosis. Finally, as with all projects exploring areas that are perceived to be highly personal, sensitive, and potentially stigmatizing, participants in some cases may have been reluctant to freely respond and provide feedback in a group setting. Despite these limitations, participants provided a wealth of information that should aid jurisdictions in assessing the appropriateness and effectiveness of their PS programs in meeting the needs of gay men and other MSM and in making adjustments to those programs where necessary.

Acknowledgements

The MAPTC and Prevention Program staff at CDPHE would like to thank the following people for helping to make this formative evaluation project possible. First and foremost, we would like to thank the 101 men who participated in the eleven focus groups and one interview. It is their voices, insights, and opinions that have provided us the kind of information that can truly influence a more effective and appropriate approach to PS. We also want to thank the following people for their help in each of the six cities, especially those who took the lead in organizing the focus groups and recruiting participants. Many others assisted them and us in making this project a success. Their names are listed below and are organized by city.

In St. Louis, we thank Matt Swango of Effort for AIDS for coordinating the groups there and recruiting participants. We would also like to thank Erise Williams from Williams and
Associates and Darne Guest from the St. Louis Department of Health for their assistance as well as Dale Wrigley, also from the St. Louis Department of Health, for his recommendations and insights as we were formulating the details of this project.

In Nashville, we thank Dwayne Jenkins from Nashville Cares for taking the lead in organizing the groups and recruiting participants. We would also like to thank Patrick Luther and Eva Pea of the same organization for their assistance and Brad Beasley from the Nashville Department of Health for his insights and recommendations.

In Chicago, we thank Diane Clay from the Brothers Health Collaborative for organizing the groups and recruiting participants. We especially want to thank her for doing so with very short notice from us and for a very good turnout under the circumstances. We would also like to thank L. Michael Gipson from the same organization for taking wonderful notes as well as Ariq Cabbler for his assistance. Additionally, we thank Daniel Pohl of the Howard Brown Clinic and Tameeka Johnson of Chicago Public Health for their insights and recommendations.

In Columbus we thank Matt Movrosh of the AIDS Resource Center Ohio (ARC) for organizing the groups and recruiting participants. We also thank Sara Holmes of ARC for assistance with recruitment; Peggy Anderson and Tania Slack, also from ARC for their incredible support; and Makeda Porter and Audrey Regan from Columbus Public Health for their insights and recommendations.

In New Orleans, we thank Matthew Reese of NO AIDS Task Force for organizing the group and recruiting participants. We also thank Chris Daunis from the New Orleans Office of Public Health for his insights and recommendations.

In Denver, Prevention Program staff from CDPHE took the lead in organizing the focus groups and partners from many different organizations helped with recruitment of participants and note-taking during the groups. We thank MaShawn Moore of Denver Colorado AIDS Project for help with recruitment and for his wonderful note-taking. Rod Rushing from Denver Health Outpatient Behavioral Health Services, Rick Smith of the Treatment Education Network, Sean Wolfe and Grant Scovel from the Denver Element, Lisa Wheeler from the Hope Program, Calvin Gipson from It Takes a Village, Dustin Wiebelhaus of Gravity Denver, and Jessica Forsyth from Children’s Hospital provided tremendous help in recruiting participants for the focus groups. We also want to thank Denver based DIS (Mariska Osborne-Wells, Danny Lopez, Tom Deem, Manuel Lopez, Tracy Williams, and Ceasar Montoya) for their insights and recommendations.