

**Access to Health Care
for Transgendered Persons
in Greater Boston**



JULY, 2000

**JSI RESEARCH & TRAINING INSTITUTE, INC.
GLBT HEALTH ACCESS PROJECT**

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Executive Summary

Access to health care services for the transgendered persons has not been studied in detail. The transgender community is a population group that has experienced an increase in visibility, with only a small, concomitant increase in understanding. This study reports on four focus groups, at which over forty transgendered individuals discussed their experiences and interactions with the health care system.

The specific aims of the study were as follows:

- to identify the health needs of transgender and transsexual (TG/TS) individuals;
- to hear the experiences and perceptions of TG/TS individuals who are using the current health care system;
- to identify any barriers to obtaining services, support and/or resources;
- to assess the extent to which health care providers and systems are able to offer sensitive, high quality services that meet TG/TS consumers' needs; and
- to identify ways that health care services can be enhanced to better meet the needs of the target population.

What the study found was a system that was anything but high quality in meeting the needs of TG/TS individuals. Widespread ignorance, insensitivity and discrimination appears to be the norm. Specifically, the focus groups found the following:

- Transgendered and transsexual persons frequently encounter providers who will not treat them and blatantly say so. There is a need for education and a change in anti-discrimination law needed to change this.
- The lack of provider training on transgender issues creates insensitivity to simple issues of respect for trans people. One example is the unwillingness to address TG/TS people by the pronoun preferred by the patient/client.
- Many providers lack the knowledge to adequately treat many of the routine health care needs of TG/TS individuals when such treatment related to issues of hormone use, gynecological care, HIV prevention counseling, or other concerns related to gender or sexuality.
- Providers frequently refer to trans issues in unrelated health care situations such as setting a broken bone, filling a cavity or treating a cold. Greater familiarity with the health care needs of the trans population would reduce such incidents.



- Mental health and substance abuse treatment providers need additional training in order to work cooperatively with TG/TS clients to identify when gender issues are or are not relevant to specific mental health or substance abuse treatment episodes. Sometimes gender issues are central to mental health or substance abuse treatment, sometimes they are peripheral and sometimes they are unrelated.
- Discrimination in health insurance is the rule, not the exception. There is a need for education to encourage policy changes on the part of insurers and public policy changes on the part of legislators and regulators.



Introduction

In recent years, gender identity issues and transgender and transsexual (TG/TS, or trans) people have received unprecedented attention in research literature as well as in the popular media. Because trans individuals may experience gender discrimination along with discrimination based on sexual orientation, they in many ways fit under the larger umbrella of a gay, lesbian, bisexual, and transgender community. However, in the past five years, some research has focused specifically on the unique concerns and needs of TG/TS individuals.^{1,2,3,4} It is clear from these most recent investigations that individuals who identify as trans face discrimination and other barriers, particularly in accessing health services.

Recent estimates vary as to the prevalence of transsexuality in the general population. In the U.S., prevalence is estimated by the American Psychiatric Association's Diagnostic and Statistical Manual IV (1987) at 1/30,000 (born) males and 1/100,000 (born) females. In the Netherlands (1986), 1/18,000 (born) males and 1/54,000 (born) females were estimated as transsexual. The discrepancy between U.S. and Dutch estimates may be related to the greater availability of care for transsexual health needs in the Netherlands and/or the greater likelihood of transgendered individuals reporting their condition there.

What gaps in health care exist for TG/TS individuals, and how can they be filled? What can providers and agencies do to make a TG/TS individual feel, and be, welcome and well cared for? What resources are available to providers, agencies, and consumers to facilitate high quality health care for trans people? To explore these questions, the Gay, Lesbian, Bisexual and Transgender Health Access Project (GLBT HAP) commissioned JSI Research and Training Institute, Inc. (JSI) to conduct focus groups addressing the health care experiences and needs of TG/TS individuals. The GLBT HAP is a collaborative, community-based program funded by the Massachusetts Department of Public Health (MDPH). The program's mission is to foster the development and implementation of comprehensive, culturally appropriate, high quality health promotion policies and health care services for gay, lesbian, bisexual and transgender people and their families.

A review of current literature reveals a growing body of knowledge regarding the concerns and needs of the TG/TS community. Most of the relevant research examines HIV prevention and services, commonly by studying male-to-female (MTF) transgender or transsexual individuals.^{5,6,7} The research shows that trans individuals are at high risk for acquiring HIV. MTF



individuals appear to be at particularly high risk; in one study, 35% of MTF study participants tested positive for HIV, compared to 1.6% of female-to-male (FTM) participants. Additionally, within the MTF population surveyed, African-Americans were disproportionately affected, with 63% testing positive for HIV.⁸

While the existing research helps to identify the trans population as a group at risk for HIV infection, it also suggests that TG/TS people may be a generally ill-served or underserved population in terms of health care. Questions arise from the research, including “What factors contribute to the high reported HIV infection rate among trans people?” and “Do the HIV infection rates suggest that trans individuals are at a higher risk for other types of physical, emotional, or material suffering?” The high rate of HIV infection may be an indicator of broader difficulties that trans people face in accessing health care services.

This study has aimed to improve the health care received by trans people by exploring what a TG/TS person experiences when she/he seeks health care. The study asked participants in four focus groups to report on their experiences in obtaining routine health care as well as specialty services, and to discuss their health insurance status.

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- to identify ways that health care services can be enhanced to better meet the needs of the target population.



Methodology

Participants were recruited for four focus groups using networking within the transgender and transsexual (TG/TS) community and outreach to health care providers who have trans clients. Advertising in community centers and health centers and outreach on the Internet drew additional participants. JSI Research and Training Institute, Inc. managed the logistics for the focus groups, including training TG/TS community members to be the group facilitators.

DECISION TO HOLD FOUR GROUPS

Having identified the trans community as an underserved group, the study explored how to organize focus groups to represent the trans community. Networking among TG/TS people and organizations revealed the difficulty of establishing a singular trans community. The TG/TS world lacks a standard set of definitions, as the language for describing nuances of trans identity is dynamic, not fixed. The task of categorizing individual TG/TS people proved challenging, as potential study participants varied widely in terms of how they categorize themselves.

Two transgendered people who are activists for TG/TS issues in Boston aided in determining a meaningful and achievable structure for this study. These two individuals recommended that separate focus groups be conducted for MTF and FTM trans individuals. They also suggested grouping participants by age, since the perspectives and experience of youth and adults were likely to differ significantly due to the vastly greater resources available now to trans youth and the cultural/political changes as well as medical advances that have occurred over time. For example, the study anticipated age-related differences in participants' experience with hormone use and sex reassignment surgery (SRS).

It was agreed that the most important variable around which to build focus groups should be TG/TS identity. However, trans identity by its very nature belongs to an individual for whom traditional gender definitions may not fit. Because of the finite allowable number of focus groups, the gender identity categories in this study were limited to two key groups: MTF and FTM. It was acknowledged that this strategy would tend to exclude biologically intersexed and/or self-identified ungendered individuals. Another consideration was that people who identify as male or female transsexuals might see themselves as unlike transgender individuals; each focus group was likely to comprise two sub-cohorts (transsexual and transgender).



Some transgender and transsexual individuals now see themselves only in their new or current gender identity. For example, an MTF might just identify as “female” rather than “trans.” Despite the possibility of discomfort between members of these two sub-cohorts, merging both groups allowed the study to research what were potentially very different health care needs and experiences (see “Findings,” below).

Four focus groups were planned, each determined by trans identity and age, as follows:

- adult male-to-females (MTF);
- adult female-to-males (FTM);
- youth male-to-females (MTF); and
- youth female-to-males (FTM).

A youth was defined as someone age 25 or under.

SELECTION OF FACILITATORS AND PARTICIPANTS

The groups were structured to be facilitated by trans individuals from the local community in order to build trust among focus group participants and to ensure the integrity of the study. Facilitators were sought who had experience in leading groups. Ideally, the study would have engaged only facilitators with experience leading groups; however, this was impossible.

A facilitator was chosen for each group who had the same MTF or FTM self-designation as that group’s participants, although each group would comprise individuals who self-identified in various ways, including as transgender, transsexual, male or female. All of the selected facilitators were adults.

To fill the focus groups, the facilitators were asked to recruit community members. The facilitators were encouraged to be open to group participants whose self-identity differed from theirs; for example, a transsexual facilitator needed to be open to people who identify as transgender.

For both of the adult groups (MTF and FTM), the facilitators were able to recruit all the participants. For the MTF youth, the adult facilitator had experience working with GLBT youth and personally knew many potential participants, but would have been unable on her own to recruit a group of the size and diversity that eventually participated. A transgender female with many youth contacts helped to recruit participants. JSI staff recruited most of the participants for the FTM youth group. The facilitator was an adult who works with TG/TS youth and is the director of a local transgender agency. A notetaker was present at each group.



A focus group moderator's guide was developed (see Appendix 2) with assistance from the facilitators.

TRAINING OF FACILITATORS

The facilitators for both FTM groups and the facilitator and co-facilitator/notetaker for the MTF youth group received training from JSI. The facilitator for the MTF adult group had previous experience leading discussion groups, and did not receive the full training offered by JSI.

JSI staff trained the facilitators on qualitative research, interviewing and listening skills, preparing for and conducting a focus group, and improving interviewing techniques. Elements of the training, along with feedback from the trainees, were later incorporated into a focus group facilitation guide tailored to this study.

Even with appropriate training for community-based facilitators, some bias was risked by intentionally assigning community members to help form and lead focus groups on issues crucial to their own lives. Also, while using community members to recruit and facilitate was expected to increase the comfort level and openness of a focus group, in some ways such a strategy might backfire. It was possible that focus group participants might be reluctant to share personal stories or perspectives if fellow participants belonged to the same community and might be encountered again in a different context.



Findings

This study of transgender and transsexual health care needs was purely qualitative. The findings presented here are based on information and opinions gathered from four focus groups, each including five to 14 participants. This section summarizes the aggregated findings from all four groups and is organized according to the topics discussed in each group, although not all groups discussed all of the topics below, nor did every group necessarily discuss these topics in the same order. The topics included the following:

- identity and demographic information;
- disclosure;
- health issues;
- quality and standards of care;
- accessing health care;
- relationships with health care providers; and
- participant recommendations.

IDENTITY AND DEMOGRAPHIC INFORMATION

Participants in all of the focus groups were asked to provide information about themselves in a screening instrument by telephone prior to the group, or at the focus group session. Not all participants completed the screening instrument. Of those who did, many amended its language to incorporate personal words of self-identification.

The screening instrument, (see Appendix 1) to this report, sought information including the participant's age, race or ethnicity, and place of residence. Participants were asked to describe their medical care and coverage. The participants also were asked to characterize their sexual identity in several ways, as follows:

- sex or gender;
- TG/TS identity; and
- sexual orientation.



MTF Adults

In the MTF adult group, most of the 14 participants lived in Metro Boston. Most of the participants were white; one was Asian and one was multi-racial. For the eight participants who provided demographic information via the screening instrument, the average age was 37.

The screening instrument used with this group was a pilot version, asking only one question about gender identity: “As a transgender or transsexual, are you male-to-female, female-to-male, or other?” All participants who completed the screening instrument responded that they were male-to-female. During the focus group discussion, half of the participants identified themselves as transgender, and the other half chose the term transsexual. In terms of sexual orientation, 11 participants identified themselves during the discussion as heterosexual, two said they were gay, and one said she was lesbian. Of the eight participants who filled out a screening instrument, the following self-identification information was reported:

Participant	Sex/Gender Identity	TG/TS Identity
1	Transgender	MTF
2	Transgender	MTF
3	Transgender	MTF, Transgenderist
4	Transsexual	MTF
5	Transgender	MTF, post-operative
6	Transsexual	MTF
7	Transsexual, MTF	MTF
8	Transgender	MTF, Woman

FTM Adults

The FTM adult group had 12 participants with an average age of 36. All participants completed screening instruments at the group meeting. Eleven were white and one was Latino. Nine lived in the Metro Boston area. Most of the FTM adults—regardless of their interest in or experience with sexual reassignment surgery or hormone treatment—described their sex or gender identity as transsexual (as opposed to transgender).



The table below displays how each participant in the FTM adult group self-identified, in terms of sex/gender and TG/TS identity.

Participant	Sex/Gender Identity	TG/TS Identity
1	Male, Transsexual	FTM and Trans
2	Pre-transition transsexual	FTM
3	Male, Transsexual	FTM
4	Transsexual	FTM
5	Transsexual	Male
6	Male	FTM
7	Male, Transsexual	FTM and Trans
8	Transsexual	FTM
9	Transsexual	FTM and Male
10	Male	Male
11	Transsexual	Trans and Male
12	Transsexual	FTM

Five of the participants identified their sexual orientation as heterosexual, four as bisexual, and three as gay (one specifying both gay and queer). All participants in the FTM adult group said they had health insurance and a primary care doctor. Nine of the 12 said they had undergone procedures “that would be considered to be part of sex reassignment or gender reassignment.”

MTF Youth

The MTF youth group included nine participants between the ages of 16 and 26, with an average age of 21. All participants completed screening instruments at the group meeting. Three identified themselves as black; two as white; one as Asian (Korean); and three as other (one “biracial black and white,” one “Middle Eastern/African-American,” and one “Italian and Jamaican”). Five said they were employed, three said they were students, and one did not name an occupation. Eight lived in Metro Boston.



The table below displays how each participant in the MTF youth group self-identified, in terms of sex/gender and TG/TS identity.

Participant	Sex/Gender Identity	TG/TS Identity
1	Transgender	Female
2	Transsexual/Female	Female
3	Female	Female
4	Female	Female
5	Female	Female
6	Female	Female
7	Transsexual	Male to Female
8	Female	Male to Female
9	Other	Male to Female

When asked “How do you identify when asked your sexual orientation?” six described their sexual orientation as heterosexual, and three described theirs as gay, queer or other.

Among the MTF youth, four said they were “currently taking hormones prescribed by a professional health care provider.” Of the other five, two said they receive hormones from other sources, three said they did not take hormones at all, and one did not respond. Four said they had had “a procedure that would be considered to be part of sex reassignment or gender reassignment,” while four said they had not undergone such a procedure. Six participants had health insurance, and three were uninsured. Eight participants had a regular health care provider.

FTM Youth

The FTM youth group included five participants, ranging in age from 16 to 25 with an average age of 21. Two participants provided information upon their recruitment. For one participant who is 16 years old, information was gathered from his mother after he agreed to participate. Two individuals completed the screening instrument at the group meeting. Four participants identified as white and one as other. Two lived in Metro Boston and three lived outside the Metro Boston area.



The table below displays how each participant in the FTM youth group self-identified, in terms of sex/gender and TG/TS identity.

Participant	Sex/Gender Identity	TG/TS Identity
1	Transsexual	Male
2	Transsexual	FTM
3	Transgender	Male
4	Male	FTM
5	Female, Transgender and Queer	FTM, Trans and Queer

In terms of sexual orientation, three participants identified themselves as bisexual, one as “queer” and one as “none.” Two participants were covered by their parents’ insurance, one had MassHealth, one had insurance through school, and one participant was uninsured.

DISCLOSURE

In all four groups, participants discussed the difficulty of choosing when and how to disclose their transgender identity to a health care provider. Some of the MTF youth felt it was not always necessary to inform health care providers of their gender status: “What does being transgender have to do with my eyes?” In the FTM adult group, a participant stated, “That kind of information is on a need-to-know basis;” he reported an incident in which he needed a wrist X-ray, and providers wrote in their notes that he was a transsexual “to educate others, because it was an educational institution. That was disrespectful.” Another participant said he avoided disclosure by requesting that the providers start a brand new health chart at each visit: “I didn’t want any evidence [of being female].” Other participants were adamant about the need for disclosure: “That’s the first thing you do when you see a doctor,” said one FTM adult.

A feeling of trust in a primary care physician was a factor that encouraged disclosure. Some of the MTF youth, acknowledging the value of disclosure to the quality of their health care, said they actively seek out friendly, knowledgeable providers. One MTF adult said she called a clinic in advance to ask whether they were “TG/TS-friendly.” Another MTF adult described a time when she “finally blurted it out” during an examination and found the provider was “very open” to her being a transsexual.



The lack of expectation of continuity in one's health care argues against disclosure, for some participants. One FTM adult said he had not disclosed his gender identity to his provider. He stated,

I'm afraid...I have had some bad experiences with health providers...so unless I'm convinced that I'm going to be with them a long time, I don't want to come out.

Safety concerns can deter disclosure. One of the MTF youth described a nationally publicized 1995 incident in which a fire response team refused to treat an injured transgender individual, leading to her death. The MTF youth discussed concerns about safety upon disclosure outside of Massachusetts, which they perceived as progressive in terms of gender orientation and sexual preference issues. MTF youth also felt that even within Massachusetts, outside of the urban center of Boston a sense of trans community was unlikely and disclosure less safe.

In all groups, participants illuminated the real risks of disclosure in terms of health coverage. An FTM youth participant said,

...(a)t best, the doctor will treat me, but report me in my medical records, which in turn will 'out' me to an insurance company that will in turn deny me health coverage for anything they say is related to me being trans.

In each of the groups, some participants said that a difficult component of disclosure was the need to inform health care providers how to refer properly to the gender of a TG/TS individual. In the MTF adult group, one participant described her anger when a provider was unwilling to refer to her as "she," and continued referring to her as "he," despite repeated requests.

HEALTH ISSUES

Participants identified a variety of health issues. In all groups, participants revealed their need for medical and psychological services common to the general population. In addition, participants described service needs particular to TG/TS individuals, mainly hormone treatments and sex reassignment surgery (SRS); and mental health and substance abuse treatment tailored to TG/TS clients.



Across all groups, participants identified needs for primary/general medical care, dentistry and mental health/substance abuse treatment. The adult MTF group saw substance abuse treatment and HIV/AIDS care as key; one MTF participant, a former prostitute, noted the deaths of 15 TG/TS friends, related to violence, substance abuse, or HIV/AIDS.

Both MTF groups considered endocrinology and hormone therapy to be major health issues. The MTF adult group said that endocrinology, mental health and primary care were their most important health care needs, but also mentioned hepatitis treatment, psychopharmacology, and ophthalmology. The MTF youth reported usage of a wide variety of health services, including primary care, mental health, dentistry, electrolysis, plastic surgery and silicon injections.

Both of the adult groups mentioned SRS as important. The MTF adult group discussed related needs, ranging from information resources about SRS to follow-up gynecological care.

The FTM youth participants cited inadequate provider education on FTM adolescent health issues. Participants in the FTM youth group mentioned their need for general/primary health care, gynecology, hormone therapy, endocrinology, dermatology, dental care, substance abuse treatment and mental health support, including treatment for depression and anorexia.

Hormone Therapy

Within each group, participants comprised a wide range of personal experience with hormone therapy and SRS. For example, in the FTM adult group, several participants said they had undergone surgery to reconstruct their bodies; one person said he did not want to take hormones or modify his body through surgery. Participants who had undergone or wished to undergo these therapies described a variety of hurdles to obtaining desired services.

In the MTF adult group, discussion focused on how participants used hormones and their concerns about the long-term medical effects of hormone therapy. Many participants in the MTF adult group said they do take or have taken hormones without medical supervision; one participant said she had increased her own dosage of hormones in order to speed her transformation. Another participant reported a stroke, leg swelling and kidney damage that she believes may be due to prolonged use of hormones.

In the MTF youth group, participants discussed the amount of therapy and exams required in order to obtain hormone therapy: “Health care providers want too much from you to give



you so little.” Even at a Boston clinic known to welcome TG/TS people, one MTF participant stated that hormone therapy only was offered due to client demand. Participants agreed that self-advocacy was critical to obtaining hormone therapy, as well as other health care.

One MTF youth cited obstacles to obtaining hormone therapy while she was in the care of a state run agency. “[The agency] is so vicious towards transsexuals.” This participant stated that she was able to obtain hormone therapy more easily in prison than through this public agency.

In the MTF youth group, of seven participants using hormones, several reported obtaining their hormones illegally and one participant said she obtained prescriptions another way:

I don't want to wait around six months so someone could tell me, 'you are what you say you are.' I started calling in prescriptions under my father's name and it worked.

Some in the MTF youth group said they had obtained hormones from friends, due to a lack of other options.

Several participants in the MTF youth group believed that inconsistent provider implementation of standards for TG/TS health care limits their access to hormone therapy. The group shared a perception that providers are moving toward standards, signifying a readiness to address the needs of TG/TS clients. However, although the standards may recommend prescription of hormones, participants anticipated that access to hormones will come slowly because standards are not universally acknowledged or applied. An MTF youth participant said that at one health center, providers told her that decisions regarding a hormone prescription for her were “on hold” while the agency established therapeutic guidelines. Another participant, in an effort to obtain hormone therapy, showed her practitioner the TG/TS health care standards published by the Harry Benjamin International Gender Dysphoria Association, Inc.; until then, the practitioner had been unaware of these standards.

Participants in the FTM adult group who had not used hormone or SRS therapies described problems related to providers' ignorance about TG/TS conditions:



I'm not interested in medically transitioning, but I want the recognition of masculinity in terms of getting called by male pronouns....it's not like I need access to immediate hormones and surgery, but I need the respect and people to know that I am uncomfortable with a lot of parts of my body.

Mental Health Issues

In the area of mental health, many participants reported distressing experiences. In the FTM adult group, participants said they often have to educate therapists on transgender issues. One participant reported that a therapist asked him, “Why didn’t you just stay a woman?” Another participant stated that a mental health provider said to him, “You’re just a different kind of woman;” the participant described feeling hurt and insulted by this comment: “If I could’ve lived as a ‘different kind of woman’ it would’ve been a lot easier.”

In the MTF youth group, participants stated that in some instances, mental health consultations are only sought to satisfy a prerequisite for obtaining hormones. Several MTF youth described their disappointments with the mental health care they had received, mentioning therapists’ lack of experience with trans people; therapists’ lack of experience with TG/TS youth; overcharging by therapists; and being “bumped between therapists” at an agency.

The adult MTF group presented a different perspective on mental health and hormones. The majority of participants in the MTF adult group said they currently were seeing a mental health practitioner, in some cases due to mood swings caused by hormone therapy. Other mental health problems reported by MTF participants included depression, suicidal feelings, anorexia, difficulty in decision-making regarding SRS, and treatment for post-traumatic stress disorder after being raped.

When mental health needs include treatment for substance abuse, TG/TS people face special barriers, according to participants. Many saw the mental health component of substance abuse treatment as insensitive to and ineffective with the particular issues of trans people. One MTF adult said that during his substance abuse rehabilitation in a hospital, providers avoided discussing gender issues, “which is ironic, as [gender issues] had everything to do with it.” An FTM adult said that finding a therapist was difficult when he began recovery from substance abuse, because therapists refused to help him deal simultaneously with his substance abuse and gender issues: “[I was told], ‘Deal with your substance abuse, and then come back.’”



QUALITY AND STANDARDS OF CARE

All groups were guided to establish definitions of quality health care and evaluate the quality of care they have received. In all four groups, participants agreed that quality health care hinged on providers' willingness to listen, learn, and allocate time to discuss conditions and issues unique to TG/TS people; "It's more than just reading your chart," said one MTF youth participant. Some participants said that the quality of care is greatly helped by access to continuity of providers and consistency in policies for health care. In all groups, participants felt that medical providers' ignorance compromised the quality of care.

In the FTM adult group, one participant said that a provider who is not sure what "transgender" means ought to let the client know: "It is unethical for them not to do that... We're supposed to be giving informed consent to be treated. So we are entitled to know, reasonably, if they have any experience [with transgender issues]."

In the MTF youth group, participants raised the point that a health care experience included not just one's interaction with a provider, but also her interactions with receptionists and other staff during the medical visit. An FTM adult echoed this perception: "I think it is... important for the support staff to be comfortable, because they are the gatekeepers." FTM youth said they frequently encountered verbal abuse and condescension from frontline health care staff such as receptionists: "I can't even make it through the front door without staff staring at me, laughing at me or whispering about my gender presentation." In the FTM youth group, all participants agreed that they did not feel safe receiving health care; one described his health care experience as "traumatizing."

Provider acceptance of one's gender self-identification was a key aspect of quality health care. An FTM adult said that it made him uncomfortable when his provider "kept referring to me as 'people like you.'" One FTM youth found experiences with gynecological care especially upsetting: "There is a lack of sensitivity when I have to have a gynecological examination... The doctor was not sensitive to the fact that I experience myself as male and that this experience was overwhelming for me." Said one FTM adult, "I think for me it is respect and a willingness to respect your pronoun. I found that to be a huge problem. As somebody that hasn't done any body alterations, it's hard for people to switch pronouns and accept the pronoun [that I prefer]."

The adult FTM group agreed that the quality of health care was enhanced when it was possible to see the same individual provider at each health care visit:



There are residents (who) are interested, but if I impart a piece of information to one, and...see a different resident the next time, it doesn't give me any continuity and I have to explain my whole story over again.

In the MTF youth group, there was discussion about a provider that is sensitive to TG/TS health issues, but whose quality of care is compromised by a protracted process of creating standards for care of TG/TS individuals. One participant in the group said that her hormone treatments were delayed for several months while a policy was established regarding the type of treatment she needed.

ACCESSING HEALTH CARE

Access to health care had two components, according to participants: one, locating providers who were knowledgeable about TG/TS people and health issues; and two, securing and paying for specific needed services.

In all groups, participant statements suggested that their discomfort in the health care system had the potential to limit their access to care at any point along the continuum from seeking care to obtaining and paying for it. For example, FTM adult participants said "For ten years I didn't go to a doctor at all," and "I didn't go to a dentist because I knew she wouldn't be comfortable." Another FTM adult said he would only access care if he were very ill: "I just don't want to be in a medical environment and be vulnerable to all the [difficulties] we've been talking about."

A lack of trust in providers hinders some participants from submitting to an HIV test. One participant in the FTM adult group said he was reluctant to describe his sex life to a provider, and therefore "would not talk to one of these doctors about safe sex." In the same group, one participant said he was reluctant to be tested for HIV, because of the questions it might spark from a doctor.

Locating Knowledgeable Providers

In each group, participants described how they found providers. While some participants used HMOs, teaching hospitals and community health centers to locate and access services, a variety of alternative means were mentioned in all groups. For example, adult FTM participants mentioned the Internet, networking in the trans community, friends, co-workers, and a partner as resources for locating health care providers.



Beyond the basic standard that providers be educated about trans issues and conditions, participants varied in their “wish list” for a provider setting. Some participants sought gay-identified clinics, while others avoided them. An FTM adult who has a child mentioned the difficulty of finding a family health care setting where providers were comfortable with his being a parent. Another FTM adult said, “I go someplace where they see a lot of us [TG/TS people] so if I need to see somebody in a related area [I feel more comfortable].”

In the MTF youth group, a participant who did not live in an urban area said that she had found appropriate providers in Boston, but “I have to come here every time I need to see someone. It is really inconvenient.” In the FTM adult group, participants discussed the greater difficulty in accessing quality care that might be experienced by people living farther from a city, “people who are less socially sophisticated, or people who speak different languages.”

Referrals within the health care system may not always be safe, according to participants. One FTM adult described what happened when he followed up on a referral for surgery:

I assumed that since I was at [a trans-friendly medical center] it would be fine, and I had [had] other surgery there that was absolutely wonderful...He asked about the scars on my chest [from reconstructive surgery], and when I told him what they were, his mouth dropped open and bounced off the floor, and he said, ‘What are you talking about?’...That was it. I was packed up and sent away.

A similar anecdote was told by an FTM youth:

I was referred to a specialist and my doctor never told the specialist about my condition and the fact that I was on hormones...the specialist was harsh with me and treated me like I had mental health problems stemming from the fact that I was transgender.

In the FTM youth group, participants discussed a lack of resources available from providers. One participant said that his local mental health provider’s limited references kept him “locked” into one circle of providers.

All groups discussed resources outside the conventional health care system that can provide information and support for TG/TS people. In the FTM adult group, one participant said,



“We have to be our own physicians in that we have to interact with other people going through the same thing and find out what [they] are doing.” For participants in the FTM youth group, the Internet was a crucial resource, offering a safe forum for finding current, relevant health information in both Web sites and chat rooms. In the MTF adult group, many had used the Internet to locate health care information, and one participant said she had used it to find the surgeon in Europe who performed her SRS surgery.

Participants in all groups said that regardless of their ability to find appropriate health care providers, securing access to needed health care still presented problems. “I was actually turned away [from an emergency room] because the doctor said he did not treat people like me,” said one FTM youth.

Securing and Paying for Needed Services

Participants’ comments reflected that the trans population shares the challenges that face the general population in securing health insurance; one MTF youth said insurance is difficult “to come by if a person is not in school, or does not have a job that includes insurance.”

Medical needs and concerns specific to being trans appear to make the journey toward health insurance especially tricky. One FTM adult reported that TG/TS people reverse the typical process of finding health care: “We choose the doctor first, and then the insurance. And that can be a huge barrier to getting care.”

In all groups, participants expressed fear of disclosing their trans identity to insurers, for fear of facing exclusions in or loss of their health care coverage. In the FTM youth group, a participant said, “Even when I do work and pay for an HMO, they don’t cover my health care cost because I have identified as transgender.” One FTM adult said that his health insurance plan specifically excludes transsexual surgery, while another said he did not know what his insurance covered: “I’m almost afraid to raise the issue. I haven’t told my employer, so I’m not sure what the hell I’m entitled to.”

One FTM adult, after he had enrolled in an insurance plan, did not want to inform the insurance company that he was TG/TS: “It wasn’t just finding a primary care physician...there were extra steps I had to take [to ensure quality care]. I had to say, ‘Please don’t put anything in your records at this time.’” Another FTM adult wanted to go outside of a health care plan for mental health treatment:



...but I was afraid that if I put down the reason I wanted out-of-network coverage, it would flag my being a transsexual and then I might lose my coverage for endocrinology and hormone therapy. So I withdrew it and opted to pay out of pocket.

In the MTF youth group, participants who had health insurance said that basic services were covered, but not endocrinology or hormone therapy. The MTF adult group's statements corroborated that the lack of coverage for hormone therapy and/or SRS by insurance plans, SSDI, or Medicaid is a barrier to accessing these services.

In the FTM youth group, participants discussed ways to circumvent the policies of health insurers in order to obtain services. Participants said that some providers will report falsely that a patient requires therapy for a hormone imbalance, to ensure that insurance will cover the costs of hormones. An FTM adult said, "We don't have to just be experts on transsexuality; we have to be experts on the health care system." Another FTM adult said, "We have to finesse the system because most things aren't covered by insurance."

Like the general population, trans people are vulnerable to limits that provider systems place on the amount and duration of treatment. In the MTF adult group, participants agreed that HMO limits on mental health counseling presented a hardship.

At the simple level of paperwork, standard forms can be barriers to health care for trans individuals. The MTF youth group discussed the legality of checking "male" or "female" based on one's self-described gender identity; one participant said, "There is no box for me, so as far as I'm concerned [checking my self-described gender] is not false." However, there is a lingering concern that insurers will reject claims by trans individuals if they fraudulently identify their gender.

RELATIONSHIPS WITH HEALTH CARE PROVIDERS

Trust in an individual provider and the anticipation of being listened to were the key attributes that participants identified for a positive relationship with health care systems and providers. However, most of the experiences described by participants illustrated a climate where, based on past experiences, TG/TS people mistrust providers and expect not to be listened to in a health care setting.



In all groups, participants said they had encountered humiliating treatment from providers and outright refusal to provide services. One MTF adult said that when a provider discovered her transsexuality, the provider refused to treat her and commented that she should ‘see a veterinarian’ as a medical doctor was ‘a doctor for people.’ In the FTM adult group, one participant, who has a child, described a provider’s reaction to his disclosure that he was transgender: “The change was remarkable.” The participant stated that after disclosure, the provider felt that his parenting was inappropriate and questioned why he wanted both ob/gyn care and hormones—evidence of ignorance about transgender issues, according to the participant.

In the FTM youth group, participants discussed a lack of sensitivity and awareness on the part of providers; said one participant, “They do not listen when I tell them that I have body issues and that I do not relate to my body as female.” Another FTM youth said that a doctor caused him to leave the office in tears by suggesting a birth control prescription to address his complaint of gender dysphoria: “We are being penalized for being truthful about ourselves by both doctors and health insurance companies.”

At times, unnecessary attention to his or her trans identity made participants uncomfortable with providers. Participants in the FTM youth group stated that providers focused on their gender identity despite its irrelevance to the reason for the medical visit, such as flu symptoms.

The FTM adult group agreed that a provider’s willingness to listen was the key to a good relationship:

It’s really important that you have a physician or a nurse who will listen to what our concerns are...because it’s not the average concern.

and,

We have knowledge that if they listen to us...and take that as a starting place, then they’re a lot further ahead than if they just treat us all as if we’re all the same.

In the MTF youth group, one participant shared this belief, saying that a good provider was someone who “might not have all the answers, but who is willing to listen.”

In the FTM adult group, some participants said they more quickly trust a nurse than a doctor:



I almost immediately trust a nurse. It's like they're in the trenches. They have a different demeanor with you than the doctor does.

Some FTM adult participants said they try to help educate providers, but often encounter the provider's lack of interest in and time for listening.

In the FTM adult group, a participant said he offers educational videotapes to providers, in order to educate them about TG/TS issues. He stated,

Some will watch it to see what we're about, and others will take it and not even look at it, and not even be interested... To me, how interested are they in our concerns and needs if they aren't interested in spending... half an hour to research what we might be about?

In one case, cancellations by other patients gave one physician the time to be receptive to a FTM adult participant:

The doctor spent an hour and a half with me, and after a year of fighting with [various providers], I finally had someone here who listened. And he agreed with my self-treatment and my self-assessment... but I don't know if that would've happened if the weather had been better. I would have had 15 minutes and that would have been the end of it.

Another FTM adult participant noted that not all providers are willing to listen and learn from patients: "When you have information that your primary care provider doesn't, sometimes they resent that."

In mental health units, detox centers or shelters, most of the FTM youth said they do not feel safe or accommodated: "It tends to be the staff that has more problems with me being transgender than the other clients or patients [have]." In general, this group felt that physicians and mental health providers do not want to treat FTM youth: "If they wanted to provide us services, they would treat us like human beings instead of freaks;" "I have to be deathly sick before I go to a doctor."



Some participants had preferences as to the gender of their provider. In the MTF adult group, most participants said they felt more comfortable with a female provider, although one said: “There are some males that are good...it depends on the person.” The reasons cited for preferring a female provider included participants’ feeling that it was easier to communicate with a female, as well as that they were more comfortable being examined or touched by a female, due to the gynecological and hormonal aspects of the care they required. One FTM adult participant said that gender didn’t matter, “as long as they are respectful, knowledgeable, and willing to listen to what my issues are.”

“I am looking for a doctor who will treat me like a human being with feelings,” said one FTM youth participant.

PARTICIPANTS’ RECOMMENDATIONS

All groups made specific recommendations to improve health care access and quality of services for TG/TS people.

The FTM adult group stressed that providers should be made aware of what transgender is and its implications for a person’s health and health care.

I think they have a responsibility to be educated about us before we walk in there. It’s important that they listen while we’re there, but it’s important that they have some prior knowledge that’s out there and available,

In addition, in order to feel comfortable and satisfied with their health care, the FTM adults wanted assurance that providers who are educated about TG/TS issues also are competent practitioners: “It’s important that a person not only has a sense of who...works with transgendered people, but also works well and is respected as a professional.”

The FTM youth developed these priorities for medical care: a safe provider environment that (1) can provide health care with respect to being TG/TS, (2) is educated on transgender issues, and (3) provides a way to pay for its services.



The MTF youth group agreed that education and training of staff—including providers, administrators, and reception staff—would help agencies develop competence in providing care to trans people. Participants suggested that providers and agencies create and familiarize themselves with reasonable policies and standards so that all parties involved in TG/TS health care can share the same expectations about care and procedures. Additionally, one MTF youth participant recommended that each client be treated as an individual: “We might have something in common, but we’re not all the same.”

Participants in several groups recommended that providers create and use more inclusive intake forms to incorporate TG/TS individuals, either by letting individuals self-identify their gender or, as the MTF youth group suggested, “adding an extra box.”

In the MTF youth group, one participant urged self-education and self-advocacy for TG/TS people to ensure their ability to obtain proper health care. The group agreed that access to the Internet and knowledge of how to use it would be very helpful to clients (as well as providers) for education and networking for health care information and support.

The MTF adult group asked for more research into prolonged use of hormones, and application of technology, such as MRI scanning of individuals for blood clots that hormones may cause. The MTF adults also asked that clinics that serve a TG/TS population offer full coverage for hormone therapy and SRS. They added that visible representation of trans individuals on staff and in provider publications would make TG/TS clients more comfortable in a health care provider setting.



Discussion

This study set out to investigate a premise that in accessing even the most basic health care, trans people interact with health care systems that may not be prepared and providers who may not be educated to address their needs and concerns.^{9,10} A further premise of this study was that most providers and systems neither anticipate nor fund particular services that TG/TS individuals require. The focus group findings corroborated these premises, and revealed a variety of barriers for trans individuals seeking health care.

Focus group participants offered diverse examples of the barriers to health care that they encountered. Some were subtle and some were blatant. The barriers ranged from refusal to treat to inappropriate intake forms for a trans person to the lack of insurance coverage for sexual reassignment treatments and procedures under the current health care system.

A recent report, “Lesbian, Gay, Bisexual and Transgender Health: Findings and Concerns,” published by the Gay and Lesbian Medical Association, describes the prevailing socio-medical theories that justify providers’ restrictive policies toward treatment for gender identity disorder.¹¹ In fact, many health insurers do limit health care for trans individuals by excluding sexual reassignment surgery and/or hormones from coverage.^{12,13} For example, one insurance policy excludes any

procedure or treatment designed to alter the physical characteristics of a Member from the Member’s biological sex to those of the opposite sex, regardless of any diagnosis of gender role or psychosexual orientation problems.”¹⁴

Such policy restrictions are exacerbated by a general lack of standards across the provider world for treating trans-related conditions. Thus, transgendered and transsexual individuals are correct that disclosing their gender identity may lead to loss of coverage. Participant statements in the focus groups suggest that many trans people do indeed approach full disclosure with trepidation, much as gay and lesbian individuals may fear “coming out” to their health care providers.¹⁵

As with most qualitative studies, this investigation yielded much soft information that indicates areas of concern, yet leaves much to be quantified and verified by future studies (see “Recommendations,” below). One caveat for any further study of health care access



among TG/TS people—whether qualitative or quantitative—is that much work still needs to be done in terms of effectively categorizing people who identify as transsexual or transgender. In this study, the difficulty of assigning individuals to an appropriate group presented methodological challenges and essentially limited the scope and power of the study.

The study limited itself by convening focus groups of transgendered or transsexual people who self-identified as transitioning from male to female or female to male. The study was unlikely to reveal the unique health care issues and barriers that may exist for nongendered people or others who do not identify with the concept of “transitioning” as an aspect of their gender. Additionally, the fact that all participants identified with some aspect of “trans” terminology, these groups still comprised many nuances of TG/TS identity. Within the groups, it was difficult to find patterns in participants’ experiences because individuals’ identities could not be categorized accurately enough for comparisons.

Participant statements in all four groups revealed significant emotional pain and in some cases outright fear when using the health care system. Such discomfort, unbalanced by positive experiences, clearly indicates a gap in health care access for TG/TS individuals. The obvious step forward is to work toward a situation where trans individuals can count on no less of a welcome from their health care providers than other consumers receive (see “Recommendations”).

The transgender population does not lend itself easily to conventional sociological methods of study. Two types of difficulties were identified in undertaking this study:

- group dynamics; and
- evolving language.

GROUP DYNAMICS

In each group, the fact that many participants and the facilitators knew one another most likely affected the nature of the group’s discussion. In the two adult groups, the facilitator had recruited the participants and was on a first-name basis with most of them. The familiarity within the groups may reflect the size of the trans community in Greater Boston. The familiarity among individuals in the groups may have inhibited participants from talking about their current personal issues, especially regarding sensitive subjects such as sexual behavior and drug use.

In the MTF adult group, stories about the past were often acceptable. Participants talked about drug use and sexual experience in the TG/TS community, although rarely talking



specifically about themselves. Similarly, participants in the adult FTM group talked about social issues within their community, but spoke less about their own sexual and drug issues. In one exception, one FTM adult who was gay-identified did talk about having unprotected sex.

In the youth MTF group, discussion did not touch upon personal sexual behaviors or drug use. Frank discussion of these topics may have been inhibited by the presence of the recruiter (a friend to many participants); a male note-taker from JSI staff; and a facilitator known to many youth in the community. After the group disbanded, the recruiter and the facilitator mentioned that some participants had downplayed their personal problems; the facilitator said she knew this from working with these youth and being privy to their lives.

EVOLVING LANGUAGE

The discussions in all four focus groups demonstrate the important fact that the language for describing TG/TS people and issues is not fixed, but evolving. Medical science, social construct, and personal experience each contribute to the terms that exist, and the ways people use and understand them.

Although we expected to gather straightforward information about participants' self-identifications with the screening instrument, these expectations were confounded by responses. Participants were asked to describe themselves three different ways:

1. What is your sex or gender?
2. What is your transsexual/transgender identity?
3. What is your sexual orientation?

The survey instrument allowed respondents freedom to choose more than one identification word in each question. Further, many individuals hand-wrote additional choices for the second two questions.

Participants varied widely in their cross-identification. For example, while one individual in a group might indicate a self-identification of both transsexual and transgender, another might reject the former term and select the latter. In the MTF adult group, three people who in the screening instrument identified as transsexual or female, later in conversation expressed strong dislike of the term "transgender." By contrast, in both youth groups, the term transgender was embraced by a larger proportion of participants. The apparent preference for the term "transgender" over "transsexual" among younger participants may reflect differences in both social and physical attributes among individuals, or it may indeed reflect



changing cultural norms around language over time. In any case, this observation suggests a starting point for studying the use and meaning of language among TG/TS people.

An established vocabulary for trans people and issues is needed to increase dialogue in the health care realm. Even the participants in this study had difficulty settling on words to describe and discuss themselves. Prior to the establishment of language that providers can use to discuss and address TG/TS clients respectfully and helpfully, the existing language must be studied to capture the terms and definitions most widely accepted. Attention to the language for trans people and conditions will contribute to comfortable self-identification for TG/TS people as well as dissemination of appropriate language to providers, agencies and others who address their health care needs.

Fitting people into boxes is necessary for meaningful sociological study, however, with this population, categorization proves a big challenge. Metaphorically as well as literally speaking, there is no standardized form for this cohort. In further studies of this nature, JSI recommends detailed attention to the language used in both a screening instrument and in questions for the groups' discussion. The findings of this study also suggest a need for opportunities for TG/TS people to share with health care providers appropriate language that fits and describes their many, diverse, unique identities.

In order for the health care system to better serve trans people, it must not only find ways to listen better to these consumers, but must initiate dialogue about their identities, concerns, and specific health care needs.



Recommendations

The GLBT/HAP and JSI study undertook to gather opinions and information from the four focus groups, in order to explore the following questions:

- What gaps in health care exist for TG/TS individuals, and how can they be filled?
- What can providers and agencies do to make a TG/TS individual feel, and be, welcome and well cared for?
- What resources are available to providers, agencies, and consumers to facilitate high quality health care for trans people?

In all four focus groups, a constant theme was a perception of vast provider ignorance of trans people and concerns. From the level of health care systems down to individual providers and front-line staff, TG/TS people reported provider unawareness of, disrespect toward, and outright refusal of treatment for their health needs, both basic and trans-related.

Many of the health care gaps that participants experienced stem from the discomfort they reported on initial contact with a health care system. Clearly, an immediate need exists to reduce the “front line” barrier to basic health care that many trans people reported in this study. A primary recommendation would embrace any activities to increase provider awareness of trans people and issues and to reinforce provider understanding of the basic right of all human beings to basic health services.

This recommendation is substantiated by a recent policy statement from the American Public Health Association (APHA), which urges researchers and health care workers to categorize transgender individuals as male-to-female, female-to-male or other as appropriate, and

not conflate them with gay men or lesbians (unless as appropriate to an individual's sexual orientation in their preferred gender) as well as acknowledging the variation that exists among trans individuals.¹⁶

The APHA report also corroborates another recommendation: that a targeted effort is needed to establish and deliver to health care providers information about appropriate language pertaining to transsexual and transgender people, conditions and procedures. The APHA report reminds the provider community to “refer to them [trans individuals] as the gender with which they identify,” and “be sensitive to the lives of transgendered individuals



and treat them with dignity and respect.” JSI, too, believes that a targeted effort is needed to remind providers, especially “front lines” personnel, to affirm each patient’s human dignity by holding assumptions in check, and listening and responding to the patient’s self-description of identity and self-assessment of health care need.

A further step would encourage providers to examine or develop, and then adopt, standards for transgender/transsexual health care. TG/TS people reported that they are uncertain as to what services are available, and therefore may be tempted to find illegal means to procure and/or finance particular services (especially SRS and hormone therapy). Besides being unlawful, such resourcefulness may put consumers in medical danger, as much needs to be learned about safe and proper hormone dosage. In pursuit of appropriate provider standards for trans-related medical care, clinical research is needed into the long-range affects of prolonged use of hormones.

Finally, it is recommended that a deeper study of the interaction between trans people and the health care system takes place. In addition to further qualitative exploration, we recommend a quantitative study to map more precisely the health care gaps for TG/TS people and to assess in more depth the numbers, diversity and geographical clustering of trans individuals throughout Massachusetts. Such a study might include employment, socioeconomic status, age, and specific health care coverage of self-identified TG/TS participants. Any information-gathering effort that can help determine the characteristics and needs of a trans community and/or its sub-communities will help open provider arms and close the health care gap.



Endnotes

- 1 Health Concerns of the Gay, Lesbian, Bisexual, and Transgender Community (2nd ed.) (1997). Prepared by The Medical Foundation.
- 2 Clements K., Wilkinson W., Kitano K., Marx R., (1999). HIV Prevention and Health Service Needs of the Transgender Community in San Francisco. IJT 3, http://www.symposion.com/ijt/hiv_risk/clements.htm
- 3 Clements, K. (1999). The Transgender Community Health Project: Descriptive Results. Prepared for the San Francisco Department of Public Health.
- 4 Mason T., Connors M., Kammerer C. (1995). Transgenders and HIV Risks: Needs Assessment. Prepared for the Massachusetts Department of Public Health, HIV/AIDS Bureau. Gender Identity Support Services for Transgenders (GISST).
- 5 Clements K., Wilkinson W., Kitano K., Marx R., (1999).
- 6 Clements, K. (1999).
- 7 Mason T., Connors M., Kammerer C. (1995).
- 8 Clements, K. (1999).
- 9 Health Concerns of the Gay, Lesbian, Bisexual, and Transgender Community (2nd ed.) (1997). Prepared by The Medical Foundation.
- 10 Haynes, R. (1998). Towards Healthier Transgender Youth. Crossroads. Winter, pp. 14-15.
- 11 Gay and Lesbian Medical Association, "Gay, Lesbian, Bisexual and Transgender Health: Findings and Concerns," January 2000
- 12 Tufts Health Plan, Point of Service Plan (October 1998). Exclusions and Limitations.
- 13 Oxford Health Plans (October 1998), Small Freedom Plan POS. Section IV: Exclusions and Limitations.
- 14 Oxford Health Plans (October 1998).
- 15 Access and Use of Health Services by Lesbians and Gay Men in the Greater Boston Area: An Exploratory Study (1997). Prepared by John Snow, Inc.
- 16 "Policy Statements Adopted by the Governing Council of the American Public Health Association, November 10, 1999."



Appendices

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**APPENDIX 1: GLBT HEALTH ACCESS PROJECT: FOCUS GROUPS
SCREENING AND RECRUITMENT INSTRUMENT**

PURPOSE:

To identify people who meet criteria for each focus group. The groups will consist of people who similarly identify and who are familiar with the health issues that affect their “community.” The intention of the focus groups is to identify specific health care needs, barriers, and other issues for each of the populations that will be attending a focus group. The focus groups will be divided into different groups based on sexual orientation or gender identity.

SCRIPT:

Hello. My name is _____ and I am working for a health care consulting firm called JSI Research & Training in Boston. The Gay, Lesbian, Bisexual and Transgender Health Access Project has commissioned JSI Research & Training to conduct focus group research in order to better understand the health care needs of different groups based on sexual orientation or gender identity. We will pay people a stipend of \$40 to participate in one of the two hour groups.

(Circle answers)

Do you think you might be interested in participating? YES NO (THANK THEM AND SCREEN OUT)

Can I get your first and last name, and a telephone number where I can reach you. (If they do not want to give their full name, an alternate name may be used.)

FIRST NAME	LAST NAME (OPTIONAL)
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HOME TELEPHONE NUMBER	OTHER NUMBER (I.E. WORK) (OPTIONAL)
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If they need to call us for any reason prior to the focus group, they can call (617) 482-9485.

We would like to have you participate but first we have to ask you a few questions to determine if you are eligible, ok?

1. We are currently recruiting people from the trans community who identify as female to male transgender or transsexual. Do you identify with this group?
YES NO (SCREEN OUT)
2. For this group, we are recruiting people who are under 26 years of age? Are you under 26 years of age?
YES NO (SCREEN OUT)



3. In the past year, have you had any contact with a health care provider or health care service?

YES NO (SCREEN OUT SCREEN OUT, UNLESS THEY DID NOT SEE A PROVIDER DUE TO BARRIERS THAT PROHIBITED THEM FROM GETTING CARE OR THEY HAVE USED THE BLACK MARKET TO OBTAIN HEALTH CARE SERVICES NOT OFFERED BY PROFESSIONAL HEALTH CARE SERVICES)

4. The focus group will be taped to insure that we do not miss any information, but all information will be confidential. All the information that you will share will only be reported in summary; in other words, no one outside of the group will know who said what. Is this ok?

YES NO

I would also like to ask you twelve questions, which we will use to develop the focus group guide. Ok? You can skip any questions that you do not want to answer. (Circle answers)

1. What is your gender identity (or sex identity)?

Transgender Transsexual Male Female Other _____

2. As a trans identified person, how do you identify?

Male to Female Female to Male Trans
 Male Female Other _____

3. How do you identify when you think of your sexual orientation?

Heterosexual Gay Lesbian Bisexual
 Heterosexual Other (Queer, Questioning/Unsure) _____

4. What is your age? _____

5. Which race/ethnicity do you identify with?

Black or African American
 White
 Hispanic or Latino
 Asian or Pacific Islander
 Other: _____

6. What is your employment or student status?

FULL-TIME JOB (MORE THAN 30 HOURS/WEEK), PART-TIME JOB (LESS THAN 30 HOURS/WEEK), STUDENT (FULL-TIME OR PART-TIME), UNEMPLOYED



7. What city or town is your primary residence? _____

8. Are you currently taking hormones that are prescribed by a professional health care provider?

YES NO (Are they receiving hormones from other sources? YES NO)

9. Have you had any procedure that would be considered to be part of sex reassignment or gender reassignment surgery?

YES NO

10. Do you currently have insurance coverage?

YES

Where do you receive your insurance coverage through (employment,parent,etc.)?

Services covered/not covered by health insurance (i.e. GRS surgery, hormones,etc.)

NO

Do you currently receive any assistance to cover your health care costs?

11. Do you have a health care provider that you can see when you need medical care?

YES NO

12. What do you consider to be your most important health care need? Describe any barriers that you have experienced trying to receive this care.



APPENDIX 2: FOCUS GROUP GUIDE IDENTIFYING THE HEALTH SERVICE AND SUPPORT NEEDS OF MALE-TO-FEMALE TRANSGENDERS AND AND TRANSEXUALS TWENTY-FIVE YEARS OF AGE AND YOUNGER
DATE: FEBRUARY 22, 1999 — 7:00 PM TO 9:00 PM

OBJECTIVES AND GROUP COMPOSITION

(a) *Statement of Group Objectives*

To explore the experiences and perceptions of transgenders and transsexuals who are using the current health care system.

- To identify the health needs of transgenders and transsexuals in Massachusetts.
- To learn about their perceptions and experiences in the present health care system.
- To identify any barriers to obtaining services, support and/or resources.
- To identify whether the services provided are sensitive quality services meeting their needs.
- To identify the degree to which the current health care system meets their needs.
- To understand how services may be enhanced to better meet the target population's needs.

(b) *Identification of Group Composition*

- Five to twelve participants
- Male-to-Female transgenders or transsexuals
- Youth who are twenty-five years old or younger
- Who have attempted to access health care services within the last year.
- Participants who seek health care in Massachusetts

(c) *Materials Needed*

- Flipchart
- Markers
- Tape
- Tape recorder/ cassettes
- Name tags
- Focus Group Guides for facilitator and notetaker
- Notepads and pens for facilitator and notetaker



I. INTRODUCTIONS AND INSTRUCTIONS (10 MIN)

INTRODUCE FACILITATOR AND RECORDER

Welcome. I would like to begin by thanking everyone for coming to the focus group, and by introducing myself and my colleague. My name is _____, and I have been trained as a focus group facilitator by JSI, which is the public health organization that is holding this focus group. My colleague, _____, is _____, and his/ her role is to be a second observer and notetaker to make sure that I get everything people have to say.

STATEMENT OF GROUP'S PURPOSE

The goal of this group is to explore the experiences and perceptions that you have had using the current health care system.

JSI is talking with many different groups of people as part of the Gay, Lesbian, Bisexual and Transgender Health Access Project to understand their experiences accessing and receiving health care services in Massachusetts. We are interested in getting your input to learn whether and how services might be enhanced to best meet your needs.

I would like to spend the next hour and a half talking with you about your views and experiences accessing and receiving health care services, and how being transgendered or transsexual has played a role in these experiences. The information that you share with us today will be documented in a report. This report will assist the Gay, Lesbian, Bisexual and Transgender Health Access Project in supporting and promoting the health care needs of the transgender and transsexual community.

In order for me to fully concentrate on everyone, I am going to audiotape this session. This helps me to review the session later on, and to ensure that I get everything that you say—in your words. This tape will not be shared with anyone other than JSI Research and Training Staff, and what you say will never be linked with your name in any report.

GUIDELINES

There are a few guidelines that I would like to share with you.

- We need your honest answers so please speak freely. Anything you say will be confidential. All the information you give will be shared with others only in summary; in other words, no one will know who said what.



- There are no right or wrong answers. We are interested in your thoughts and ideas. If you agree or disagree with something someone has said, please let me know.
- And, as we only have an hour and a half to get through a lot of information, I will need to keep the group focused on the objectives of this group.
- We want to value and confirm all people’s identities, so please respect how other group members identify.

PARTICIPANT INTRODUCTIONS

So, let’s get started. I would like each of you to introduce yourself by giving your first name only, and telling us about any health services that you have used in the last year. Gary will list each of the health care services on the flip chart.

II. BODY OF THE INTERVIEW

HEALTH CARE SERVICES (FLIP CHART)

1. Now, let’s review the list to make sure that we all agree on what services can be considered to be health care services.
 - Go through their list and make sure that it matches the health care service categories that are listed below. Correct any inconsistencies between the list that they provided and the definition that is below- you may want to read the definition to make sure that they understand what services are included when we refer to health care services.
 - Health care includes the following services: primary care, mental health and professional counseling, substance abuse, specialty care such as the treatment of HIV disease, medical surgery and urgent care such as emergency room service.

QUALITY HEALTH CARE (FLIP CHART)

2. How would you describe “*quality health care*”?

This can be a brainstorm session, but try and find the major themes that the group has mentioned.



PROVIDER AND QUALITY HEALTH CARE

Now, I would like us to talk about the type of provider who is able to provide the quality health care that we have just listed.

3. First, What characteristics would you attribute to a provider who provides quality health care?
 - Describe any ideal characteristics for a provider
4. Do you all have a health care provider? [refer to the screening tool]
 - How did you find your health care provider?
5. Some people may feel that the health care that they receive as a transgender or transsexual is not of high quality. How would you describe the quality of the health care that you receive from your provider?
 - Give specific examples
 - Describe any aspect of the care that you have received.
 - Tell us about any experiences about the care that you've received.
 - What was good about it?
 - What would you have changed?
6. What suggestions would you make for your health care provider to improve the quality of health care?
 - Consider a scenario: The Director of your local community health center wants to know how to improve the quality of health care that providers in Massachusetts offer to transgender or transsexual clients. What suggestions would you have?

RELATIONSHIP WITH HEALTH CARE PROVIDER

7. Where do you turn when you have a health care concern?
 - Has there ever been a time that you have not contacted your health care provider, even though you needed health care services?
 - When do you seek health care services?
 - *(When you feel sick, urgent care/ER, Check-up, hormones, specialty services?)*



For the next few questions, think about your relationship with your provider.

8. How would you describe your relationship with your provider?
 - What issues have you felt comfortable sharing with your health care provider?
 - Please talk about any issues that you have not felt discussing with your health care provider?
9. Have you told your provider about your gender identity?
 - Describe how you think telling your provider about your gender identity has affected the health care that you receive? ...or will affect the health care that you receive?
 - (NOT's) Describe how you think that NOT telling your provider about your gender identity has affected the health care that you receive?or will affect the health care that you receive?
 - (NOT's) Describe the reasons for not telling your health care provider
 - (NOT's) What do you think would help you feel more comfortable about disclosing your gender identity?

HEALTH CARE SERVICES ACCESSED

10. Review the services that are listed on the flip chart.
 - What other services not mentioned have you EVER used?
 - What additional services have you wanted to use but haven't? Please describe.

ACCESSING HEALTH CARE

11. Considering the services [see flipchart], how did you feel about accessing any of these services?
 - Are some services easier to access than others? Please explain.
 - Are there any specific barriers that have prohibited you from getting health care services? (“What about cost”)
 - What do you think might be done to make the health care services or resources that you use more user friendly?



12. How do you think that being transgendered or transsexual has affected how you seek the health care services that you receive?
- Have you been able to access these services when you've needed to?
 - What services have you had difficulty accessing?
 - How have you been able to find the health care services that you currently use?
OR.....that you have used?

III. CLOSING

1. Summarize key themes around each topic.
2. Ask if there are any other ideas, and ask them if you have missed anything.



APPENDIX 3: RESOURCES

BOOKS

Transgender Care : Recommended Guidelines, Practical Information, and Personal Accounts

Gianna E. Israel, Donald E., II., Md. Tarver, Joy Diane, M.D. Shaffer

Temple University Press, 1997

Medical, Legal and Workplace Issues For The Transsexual

Sheila Kirk, MD and Martine Aliana Rothblatt, JD

Together Lifeworks, 1995

Physician's Guide to Transgendered Medicine

Sheila Kirk, MD

Together Lifeworks, 1997

Gender Outlaw : On Men, Women, and the Rest of Us

Kate Bornstein

Vintage Books, 1995

Read My Lips: Sexual Subversion and the End of Gender

Riki Anne Wilchins

Firebrand Books, 1997

RESEARCH AND ARTICLES

American Public Health Association (1999). The need for acknowledging transgendered individuals within research and clinical practice. Policy Statements Adopted by the Governing Council of the American Public Health Association, November 10, 1999. Available online at <http://www.apha.org>.

Access and Use of Health Services by Lesbians and Gay Men in the Greater Boston Area: An Exploratory Study (1997). Prepared by John Snow, Inc.

Clements K., Wilkinson W., Kitano K., Marx R., (1999). HIV Prevention and Health Service Needs of the Transgender Community in San Francisco. IJT 3, http://www.symposion.com/ijt/hiv_risk/clements.htm

Clements, K. (1999). The Transgender Community Health Project: Descriptive Results. Prepared for the San Francisco Department of Public Health.



Gay and Lesbian Medical Association (2000). Lesbian, Gay, Bisexual, and Transgender Health: Findings and Concerns. Available online at www.glma.org.

Haynes, R. (1998). Towards Healthier Transgender Youth. *Crossroads*. Winter, pp. 14-15.

Health Concerns of the Gay, Lesbian, Bisexual, and Transgender Community (2nd ed.) (1997). Prepared by The Medical Foundation.

Mason T., Connors M., Kammerer C. (1995). Transgenders and HIV Risks: Needs Assessment. Prepared for the Massachusetts Department of Public Health, HIV/AIDS Bureau. Gender Identity Support Services for Transgenders (GISST).

SELECTED INTERNET RESOURCES

www.glbthealth.org

The Gay, Lesbian, Bisexual, and Transgender Health Access Project

www.savina.com/confluence/hormone

A comprehensive site for hormone therapy

http://www.avitale.com/FTM_101.html

An overview of FTM experience, focusing particularly on health issues

<http://www.annelawrence.com/index.html>

Medical and Other Resources for Transsexual Women (Male-to-Female)

<http://www.hbigda.org/>

The Harry Benjamin International Gender Dysphoria Association, Inc. (HBIGDA): Responsible for establishing Standards of Care for the treatment of gender identity disorders.

<http://www.users.uswest.net/~ajgoodrum/gender101.htm>

Gender Identity 101: A Transgender Primer: An essay outlining a basic understanding of the transgendered community and the issues those within that community face.

