

# **HIV/AIDS in the Transgender Population: A Community Consultation Meeting**

**Convened by**

**The Division of Community Based Programs  
HIV/AIDS Bureau  
Health Resources and Services Administration**

May 5, 2005  
Rockville, Maryland

The Consumers Workgroup of the Division of Community Based Programs, of the HIV/AIDS Bureau, would like to thank the participants of this Community Consultation, who generously gave of their time and expertise so that we can work towards improving services to the Transgender Community in our Ryan White CARE Act programs. Some of the participants have agreed to list their names in this document. However, this was not possible for all of them. We are equally grateful to all, named and unnamed.

Tony Collins  
Transgender Health Empowerment, Inc.  
Washington, DC  
[tcollins@rtcrm.com](mailto:tcollins@rtcrm.com)

Cseneca Greenwood  
AIDS Project East Bay  
San Francisco, CA  
[cgreenwood@apeb.org](mailto:cgreenwood@apeb.org)

Jamie Feldman  
Program in Human Sexuality  
University of Minnesota  
Minneapolis, MN  
[jfeldman@umphysicians.umn.edu](mailto:jfeldman@umphysicians.umn.edu)

JoAnne Keatley  
Medical Consultation Network  
Family and Community Medicine  
University of California San Francisco  
San Francisco, CA  
[jkeatley@fcm.ucsf.edu](mailto:jkeatley@fcm.ucsf.edu)

Sofia Marrero Cruz  
Transexuales y Transgeneros en Marcha  
San Juan, PR  
[hotlatinvenus@hotmail.com](mailto:hotlatinvenus@hotmail.com)

Marlana Mink  
Youngstown, OH  
[marlanamink@yahoo.com](mailto:marlanamink@yahoo.com)

Morisane Sunny Shiroma  
Asian Pacific Islanders Coalition on HIV/AIDS  
(APICHA)  
New York, NY  
[sunnydesu@yahoo.com](mailto:sunnydesu@yahoo.com)

Brenda Thomas  
Transgender Outreach Project  
Houston, TX  
[Brenda.Thomas@cityofhouston.net](mailto:Brenda.Thomas@cityofhouston.net)

P.J. Two Ravens  
The University of Michigan HIV/AIDS Treatment Program  
Ann Arbor, MI  
[pajeho@med.umich.edu](mailto:pajeho@med.umich.edu)

Kevin J. Wood  
Northern Nevada HOPES  
Reno, NV  
[kjw\\_unltd@sbcglobal.net](mailto:kjw_unltd@sbcglobal.net)

Teodoro A. Yoder  
Manchester, CT  
[topodchiesa@aol.com](mailto:topodchiesa@aol.com)

In addition, we owe special thanks to our Consultation Facilitator, who did an excellent job of drawing out the critical information in this report from the participants.

Ben Singer  
Philadelphia, PA  
[bensinger@verizon.net](mailto:bensinger@verizon.net)



## Executive Summary

The HIV/AIDS Bureau of Health Resources Services Administration invited a diverse group of participants from across the United States to a consultative meeting in Rockville, MD, in May 2005. The meeting was held in order to discuss strengths and challenges that transgender individuals face relating to HIV/AIDS care and to their health care as a whole. The attendees also discussed barriers to care for the transgender population, and possible strategies or ways to facilitate access to care for the community. The meeting facilitator used an INDIVIDUAL WINDOW . . . HIV/AIDS CARE FROM MY POINT OF VIEW to gather this information from participants. This was adapted from the Community Window tool from Group Facilitation Methods® materials developed by the Institute of Cultural Affairs ([www.ica-usa.org](http://www.ica-usa.org)). The adaptation was an acknowledgment of range among transgender, trans-sexual and gender-variant individuals. The tool used for purposes of this consultation consisted of quadrants in which group participants wrote down their thoughts and responses to the focus questions. The headings for the quadrants were: Individual Strengths, Individual Challenges, Barriers to HIV/AIDS Care, and Facilitators to Care to Overcome the Barriers. Individuals shared their lists with one or two other people in the group where similarities and differences were noted and discussed. The small groups also reached consensus on what they felt were the most important issues. Finally, these small groups shared with the entire group the thoughts and responses they discussed. A large group discussion of the information provided by the small groups was then facilitated.

The participants shared three overarching categories of need for the transgender community that warrant attention and action from the HIV/AIDS Bureau. These three categories included: 1) education on several levels; 2) access to resources; and 3) research and data on the community.

- 1) **Education** - Participants emphasized that various audiences need to become educated about transgender issues.
  - **Medical and Social Service Providers:** Providers need additional and specialized education opportunities in order for HAB to ensure quality, client centered, and culturally-competent clinical care. Furthermore, these opportunities would assist providers in acquiring a better understanding of and respect for the needs of their transgender clients. Participants suggested that the AIDS Education and Training Centers (AETCs) might be well utilized in this effort.
  - **HRSA staff and grantees:** Participants recommended that the HIV/AIDS Bureau include trainings for HAB project officers and multiple workshops at the 2006 Ryan White All Grantees meeting.
  - **Transgender individuals themselves:** This diverse population would benefit from learning how to take care of their own needs, where to access available resources, and how to better advocate for themselves.
  - **The General Public:** Providing meaningful education opportunities to the general public about transgender people, particularly their health care challenges, would combat the stigma that is often a barrier to their receiving access to health care. Misunderstanding leads to isolation. Seeking input from a diverse group of transgender clients in the development of marketing strategies and in mainstream advertising would increase the effectiveness of these efforts.

**2) Research and Data on the Transgender Community** – Epidemiological and service utilization data used for important funding decisions does not reflect the level of HIV in the transgender population.

- Design data collection tools (including CADR and program intake forms) to include the two step model of asking for birth sex and current gender identity currently being used by the CDC.
- Partner with other agencies and research institutions to conduct clinical and psychosocial research on this community, such as research on the interaction of hormone therapies and HIV medications.
- Fund a SPNS project targeting transgender populations and treatment interventions
- Use HRSA/HAB website to establish a topic page on transgender information, resources, and data.

**3) Access to Resources** – Participants identified a number of resources that could assist in supporting better access to HIV care, including:

- A city-by-city transgender resource directory
- Mental health services specifically tailored for this community
- Widely published, accessible guidelines for hormone therapy
- Easier access to hormone therapy
- Funding for programs tailored to this community

## **Welcome and Introductions**

On May 5, 2005, the Health Resources and Services Administration (HRSA) convened a consultation with 15 representatives of the transgender community. The invited participants represented individuals from several racial and ethnic groups (Caucasian, African American, Hispanic, Asian Pacific Islander, and Native Americans), different age groups, including youth and seniors, and a variety of geographic areas (Southwest, Northwest, Midwest, Northeast and Southeast), as well as urban and rural areas.

The Division of Community Based Programs (DCBP) in coordination with the Division of Training and Technical Assistance (DTTA), located within HRSA's HIV/AIDS Bureau (HAB), organized the meeting with help from BETAH Associates. The purpose was to identify major HIV/AIDS issues from the community's perspective and receive input on how HRSA could better serve transgender individuals with HIV through its Ryan White CARE Act programs.

Several representatives from HAB were on hand for the consultation, including Associate Administrator Dr. Deborah Parham Hopson. The facilitator for the meeting was Ben Singer, founding director of the Trans Health Information Project in Philadelphia, and a researcher focusing on trans health issues in conjunction with his doctoral work at Rutgers University.

Participants were welcomed to the meeting by Dr. Jose Rafael Morales, DCBP Director, who commented that the event presented HRSA was a critical opportunity to learn from transgender communities about their HIV health care needs. Because stigma and ignorance make it hard for transgender individuals to access high quality HIV/AIDS services, he asked participants for input and suggestions on how the CARE Act could develop culturally competent programs for transgender individuals. "You are the ones who need to tell us what works and what doesn't," he said.

Dr. Morales then introduced Sera Morgan, a DCBP project officer and member of the meeting planning committee. Sera said it was a privilege to welcome participants to the meeting and expressed appreciation for their "patience, enthusiasm and energy." She acknowledged other members of the meeting planning committee: Kim Evans, Mei-Ying Li, Helen Rovito, and Eda Valero-Figueira. She also acknowledged the hard work of Sherri Greenwood and Wayne Hartzell of BETAH Associates for managing the meeting logistics.

## **What is a Project Officer?**

Dr. Morgan described the role of the project officer as being the "first point of contact for grantees" that receive CARE Act funding. DCBP manages and supports 509 Title III and IV grants. At the present time, most project officer interaction with grantees happens via phone and email. "We get a lot of our information [about HIV/AIDS

programs] from program and clinic staff on the phone, but we also need the perspectives of clients,” she explained.

She stated that HAB is aware that in many cases CARE Act programs are not reaching out effectively to transgender communities. “So we need you to share your stories to help us do our jobs better and get more people with HIV and those who are at-risk for getting HIV connected to care that makes them feel confident and comfortable,” she said.

### **What is the Ryan White CARE Act?**

Steven Young, Director of HAB’s Division of Training and Technical Assistance, welcomed participants and expressed his interest in hearing about their unique experiences over the course of the meeting. He provided them with an overview of the Ryan White CARE Act, which at more than \$2 billion is the third largest source of Federal funding for HIV treatment behind Medicaid and Medicare.

Mr. Young highlighted the fact that the CARE Act is a national program, and therefore should have some impact in all communities. “If you don’t see CARE Act-funded services in your area, we need to know about that,” he said.

He briefly explained that his Division is responsible for providing technical assistance to grantees to ensure that CARE Act programs operate efficiently and effectively in meeting the needs of those with HIV/AIDS. It also provides consumers with support to enhance their role in the planning and implementation of CARE Act programs.

### **Orientation to the Community Window Discussion Tool**

The Community Window is a tool adapted by Steven Kilkelly from the Technology of Participation® (ToP®) developed by the Institute of Cultural Affairs - [www.ica-usa.org](http://www.ica-usa.org). It records individual perspectives on access and barriers to HIV care. It enables participants to speak from personal experience or from the experiences of those they know. It can also be used to describe program or system experiences.

Mr. Singer explained that the first thing participants would do is use the tool to identify their individual strengths. He asked them to be flexible and think broadly about their strengths, as individuals, as providers, and as members of the transgender community. Examples were given. A person could have compassion in dealing with clients. Transgender individuals could be considered creative as a community.

After identifying ten strengths, said Mr. Singer, the group would separate into smaller groups, where they would compare their strengths and identify their challenges. Later, the same approach would be used to identify barriers to, and facilitators of, HIV care.



## Strengths and Challenges

Participants broke out into small groups to identify strengths and challenges they experience as members of the transgender community, and as providers of services to transgender clients.

### Strengths

Group members identified current strengths and potential strengths they bring to the table as transgender individuals. As providers, participants felt that “looking like” the clients they serve was important for building trust and making clients feel comfortable. They also expressed the potential for empathizing with their clients in a unique and valuable way. Most of the small groups identified the need for compassion in serving transgender clients, many of whom come in for services when they are in crisis. Being compassionate was viewed as a way to empower transgender clients in taking care of themselves and getting the healthcare services they need. One of the groups suggested that the community should further strengthen the network of transgender providers through outreach, training, education, and support.

The small groups also identified the need for active advocacy and good spokespeople to put a public face on the needs and experiences of transgender individuals. Many believed that given the creative and dynamic nature of transgender communities, this was an achievable goal. Other strengths identified by the small groups included:

- Cultural integrity.** The community is very diverse, an aspect of the community that should be recognized and utilized.
- Creative.** Limited services for transgender populations require that they be creative and resourceful in accessing care and services.
- Compassionate.** Transgender individuals need to teach providers about who they are and what they need while demonstrating compassion toward providers as they learn.
- Open-minded.** Transgender individuals must be open about what their needs are, especially when it comes to specialty care for gender-related body parts.
- Willingness to listen.** Transgender individuals take in a lot of information to help themselves.
- Having good self-esteem and self-knowledge about needs.** Especially from a healthcare perspective, transgender people must be able to set limitations and boundaries to get the best care possible.
- Embracing HIV as a part, but not all, of who a person is.**

Strengths identified by the groups for providers of HIV care included:

- **Holistic care.** Identifying and addressing the client’s needs in a comprehensive manner is important.

- **Cultural competency/awareness.** Everyone has the ability to be aware, and as providers it's important to know clients as people and know their stories, how they identify themselves, what terms they prefer, etc.
- **Confidentiality.** As providers, it is important to advocate for progressive disclosure, where clients understand the laws in a way that helps them know what they do and don't have to reveal about themselves.
- **Non-judgmental and understanding:** Providers should educate their clients on how to communicate effectively to get their needs addressed.

## Challenges

Some of the challenges identified by participants included the existence of “widespread myths” about what it means to be transgender. Many participants talked about the discrimination they face as transgender individuals, which can lead to isolation from the larger community, particularly in rural areas. Being HIV-positive was described as being “doubly stigmatized.”

Group members also discussed the process by which transgender individuals internalize the stigma and discrimination they experience, which can lead them to unhealthy behaviors, such as abusing drugs and alcohol, and getting hormones on the street. In addition, the absence of available mental health services acts as a barrier to addressing feelings of isolation, fear, and depression. In general, the limited availability of resources for transgender persons was noted as a significant barrier, and participants said the problem was further compounded by a lack of knowledge among transgender individuals about where to seek services.

Other challenges noted by the groups included:

- **Invisibility.** People are more aware of the existence of male-to-female people than they are of female-to-male individuals or other transgender identities such as “gender queer.”
- **Being too sick to educate providers about their needs.**
- **Lack of knowledge about what competent care is.** Transgender clients often don't know what constitutes quality care.
- **Confidentiality.** Conflicts between name and gender on medical charts can threaten the confidentiality of a transgender person, especially in emergency-room settings where other patients may hear particulars about gender or health issues.
- **Lack of transgender knowledgeable providers and specialists.** This is especially a problem in rural communities.
- **Priorities of client may be different than health system goals.** Gender-affirming needs often outweigh primary care needs. More specifically, the desire to secure hormones may supersede concerns about HIV care.
- **Lack of coordinated care.** Often, clients have to go to one place for primary care, another for HIV care, another for transgender care, another for social services, etc.
- **Security.** Transgender individuals are often shunned by their families and others. They also experience isolation from other transgender people, especially in rural

communities. Feelings of isolation can be further compounded by not “passing.” Passing means when a person on the street cannot tell you are transgender.

- **Lack of insurance.** It is difficult to get coverage for transgender-specific care, such as hormones and sex reassignment surgery.
- Identification. Many health care forms do not allow people to identify as transgender.
- **Cost of hormones.** This is a barrier for many transgender individuals, and if low-cost or free hormone therapy were made available, it could be an effective incentive to bring transgender individuals into health care services.
- **Sex change.** The cost of sex reassignment surgery is significant, and trying to find insurance coverage or financial support for these procedures is difficult.
- **Misinformation:** Having the wrong information on medications can harm transgender individuals.

*I have pretty decent health care, but I was scared to death when I made my full change over, my name change and the all the legalities, because I was afraid of what they would and wouldn't cover - namely my hormones. We have some doctors in Houston who will say, 'Oh, you have that disease because you are transgender and then you've got a \$500 bill instead of the insurance company.*

### Group Discussion on Barriers and Challenges

One of the provider participants, from San Francisco, stated that the lack of access to competent transgender health care leads to low self-esteem among transgender individuals, which results in a lack of caring about themselves, and not caring, in some cases, whether they live or die.

“I became HIV-positive at a time when I didn't care if I lived, because I could not see myself growing old as a woman,” explained the participant from Manchester, CT. Once I got access to testosterone and access to

surgery, my compliance [on HIV medications] went through the roof. I started to care. I am motivated to treat my HIV [now that I can see myself growing old as a man].”

The San Francisco provider mentioned, too, that individuals who consider themselves gender queer or gender variant do not want to live as male or female. She added that it would have been helpful to have gender queer participants, as they have different perspectives and are growing as a population.

The distinctions between being transvestite, transsexual, and transgender were also emphasized. The participant from Houston, TX, wondered if adopting an umbrella term might help transgender advocacy efforts and raise their profile. Others talked about the need to dispel misconceptions about the sexual orientation of transgender individuals. “We are gays, lesbians, and heterosexuals,” explained another. She also stated that assumptions made about the sexual orientation and gender expression of transgender individuals create a barrier to providing them with services.

It was further noted that there are some transgender standards of care, and HIV standards of care, but they are not coordinated. "As far as comprehensive standards of care, they do not exist," said the provider from San Francisco. "There are some protocols that have been replicated throughout the country, and I can provide those to anyone who wants them, in both English and Spanish," she offered. "In San Francisco, we also have protocols for youth."

The participant from Puerto Rico talked about the discrimination Puerto Rican residents must endure, which makes it very difficult to obtain basic things needed to protect their health, such as condoms, let alone support for outreach and education activities. She also talked about health issues that are unique to transgender people as a community, and to individuals who are transgender specifically. As an example, she explained that a person born male who is now female has more fat content in her blood from taking hormones, which would be important for a health care provider to understand and address in terms of care since some of the HIV treatments have an impact on fat in the system. In terms of providing HIV care, she said, it would also be important to know how hormones interact with HIV medications.

As an example of their treatment in Puerto Rico, she also relayed the story of an HIV-positive friend who was born male and lives as a female, and went to the doctor because she had necrosis. The doctor attributed the necrosis to her silicone injections, when in fact it was a side effect of her HIV medications. She said some doctors are quick to blame health problems on the fact that a person has undergone sexual reassignment treatments, without investigating other possibilities.

Another participant told the story of going to a doctor who did not detect that he was a female-to-male transgender, until he disclosed the information. The doctor was angry that he had been "fooled" and responded by making inappropriate remarks unrelated to the provision of care.

The discussion turned to access to appropriate hormone treatment, which was identified as a pivotal issue for transgender individuals. It was noted that hormones are very hard to obtain, and many transgender individuals resort to buying hormones on the street, which is not safe and can lead to serious health problems. The provider from San Francisco stated that in addition to hormones, transgender individuals use silicone and other substances to modify their bodies. She spoke of the dangers posed by underground silicone parties, where people inject cooking oil, body oil, and other substances thinking that they are injecting silicone.

The physician from Minneapolis, MN, stated that a barrier to promoting more culturally competent care is the lack of funding to teach medical residents about the needs of transgender patients. She also emphasized the pressures of the current healthcare system that demand doctors spend less and less time with their patients. She noted the absence of research on how HIV medications interact with hormones, and the existence of little research indicating which hormones are better, safer or more effective. She argued that there isn't much information available to use as a basis for

training medical residents. She noted that a barrier to the research is the fact that in “the grand scheme of things,” the transgender community is small. “Within HIV, the same thing happens,” she said, “because transgender people are a relatively small percentage of those with HIV.”

The participant from Houston, TX, questioned why the medical community was so uninformed given that the first gender reassignment surgery happened in the 1920s. “Eighty-five years later, the medical community fails to realize that we are medically dependent on them, and we don’t have a choice,” she added. A youth participant said a related problem has to do with providers who do not want to perform cosmetic surgery on individuals who are HIV-positive.

The participant from Ann Arbor, MI, pointed out that while transgender communities represent a smaller percentage of those with HIV, they have the highest rates of HIV among all populations. The provider from San Francisco added that the community must do a better job of advocating for data and research on transgender health. She further suggested that CDC’s risk categories have a lot to do with the under-reporting of transgender people in surveillance data, and said that transgender individuals are often misclassified under other categories. The participant from Oakland, CA, said that while her county health department had really “stepped out” and funded her transgender program for the last eight years, they still do not report on transgender populations in their epidemiological data. She asked HRSA to urge better data collection to capture the true nature of the HIV epidemic among transgender populations.

One of the Project Officers clarified that the CARE Act Data Report does enable funded providers to report on the numbers of transgender clients they serve. The guidance given to grantees is to let clients self-identify rather than assign a given identity to them.

One of the youth participants said that the community itself needs to be better about being visible. In her program, she encourages clients to identify as transgender, rather than, or in addition to, identifying themselves as just male or female.

Examples were given of how lack of data has an adverse impact on service availability. “I have been trying to get ADAP to cover hormones in my state, but they keep telling me that they are not life-sustaining,” said one of the participants. “I keep telling them to ask any transgender person whether hormones are life-sustaining. I would love HRSA to provide hormone guidelines to its grantees.” He also suggested that transgender populations could provide medical researchers with a lot of good information on the effects of hormones over time.

“I would really advocate especially for infectious disease doctors to have this information, if no one else,” the provider from San Francisco suggested, “because they will be the ones seeing transgender individuals if rates of HIV continue as they are.” Another participant suggested that maybe HRSA should target some of its grants

specifically to transgender-run or transgender-serving organizations and expressed concern about the power of Ryan White Planning Councils in EMAs. “ I feel that transgender people will not be served as long as EMAs have the power,” she said.

## **Discussion of Barriers to and Facilitators of HIV Care**

The small groups broke out again, following the discussion, to individually identify barriers and related facilitators to HIV/AIDS care. The resulting barriers are listed below along with corresponding facilitators for the consideration of HRSA officials.

### Barrier

Providers lack knowledge of transgender language, culture, and needs.

### Facilitators

- Mandate that funded providers meet competency standards and undergo training.
- Require grantees to demonstrate expertise/experience in serving transgender populations as part of its funding guidelines.
- Formally fund transgender education activities through its AIDS Education and Training Centers (AETC) program.

### Barrier

Transgender communities are invisible to agencies providing services. Further, the clinic environment is not comfortable and not reflective of transgender client needs.

### Facilitators

- Update provider forms or software to include a category for transgender.
- Identify transgender individuals as a special population to be served by the CARE Act, and initiate a SPNS project to establish a clearinghouse on transgender information and data.
- Hire staff from transgender communities to help provide a welcoming environment. Include photographs of transgender individuals on materials, and include articles about transgender communities in publications to convey the message that HRSA embraces all clients.

### Barrier

Many HIV prevention messages do not resonate with transgender communities, and some transgender individuals don't think HIV affects them.

### Facilitator

- With input from transgender people, develop prevention materials and messages that reflect their unique needs and experiences.

### Barrier

Transgender individuals prioritize other things over HIV, i.e, hormone treatment, housing, or substance abuse treatment.

### Facilitator

- Combine HIV services with services that meet other needs that the client may have, such as job training, housing, substance abuse treatment and, most notably, hormone therapy.

### Barrier

There is minimal insurance coverage for transgender-specific care, and transgender individuals have limited access to needed services.

### Facilitator

- Advocate for changes that will enable ADAP to cover hormones and Medicaid and Medicare to cover sex reassignment surgeries and other procedures that transgender individuals may need to be healthy.

### Barrier

Medical and insurance forms do not allow transgender individuals to identify themselves as transgender.

### Facilitator

- Change the documentation forms needed for medical and insurance purposes to allow transgender clients to self-identify.

### Barrier

Organizations serving transgender individuals lack the capacity and resources to expand or sustain themselves.

### Facilitators

- Develop funding announcements that focus on building the capacity of transgender services and transgender-serving organizations.
- Provide funding for social services and for research on transgender issues.

### Barrier

HIV programs and services are often fragmented.

### Facilitator

- Support integration of mental health, primary care, social services, and HIV care in programs serving transgender clients and others.

### Barrier

Transgender people lack access to hormone therapy.

### Facilitator

- Offer free or low-cost hormones as a way of getting transgender people connected to care or coming in for an HIV test.

### Barrier

Clients have social phobias or other mental health disorders that need to be addressed prior to HIV. Due to stigma and discrimination, transgender individuals engage in unhealthy behaviors or live in conditions that increase their vulnerability to HIV/AIDS, e.g. substance abuse, sex work, homelessness, and fear of HIV/AIDS.

- Facilitators  
Offer culturally competent and consistent counseling or therapy in conjunction with care services.
- Be open to addressing priority needs based on how the client defines them.
- Provide support groups and advocacy training for transgender clients.

### Barrier

Lack of sub-cultural sensitivity across and between groups — transgender people can be poor, coming out of prison, etc. They can face financial barriers to receiving services and care.

### Facilitators

- Offer culturally relevant training to medical and social services staff.
- Offer financial assistance and training on how to be fiscally responsible.
- Create a city-by-city transgender resource directory.

### Barrier

Having the term “AIDS” in the name of an organization or program may turn clients away.

### Facilitator

- Hold a community forum and see what the community wants to name an HIV program.

### Barrier

Exclusion from surveillance systems means there is limited data on how HIV affects transgender individuals.

### Facilitator

- Require epidemiological systems to collect data on transgender individuals so that needs can be documented and used to secure funding and resources.

The provider from San Francisco mentioned that 1 out of every 50 inmates in California corrections facilities is transgender, which means that the community is hugely over-represented in prisons. Most of these individuals are serving time for non-violent crimes.



The physician from MN suggested that there is a risk in associating free hormones with HIV programs, but that access to both transgender and HIV health care must be available to everybody, which would imply hormone treatment for transgender individuals. If hormones were made available as an incentive to get people to come in for care, this might have the unintended consequence of people becoming HIV-positive to gain access to hormones, or at least claiming that they are HIV-positive in order to receive hormones.

### **Discussion of Additional issues and topics not covered through the process**

The physician followed up the discussion of barriers and facilitators by identifying some additional barriers she faces as a provider. Unlike Hispanic, African American and other communities, she said, transgender individuals are not concentrated in one place. This makes it hard to create effective outreach strategies.

She further emphasized that part of the problem was due to a “broken” health care system that makes health providers code a certain way to get reimbursed, affords them less and less time with their patients, and prohibits them from addressing certain issues. “The whole system needs to change for everyone,” she added. Effective provider education, she said, needs to reflect an understanding of the time pressures and funding constraints faced by providers in the clinic setting.

She agreed with previous remarks regarding the use of hormones as an incentive for getting people into HIV prevention and care programs, and suggested that hormones not be used just for HIV-positive people, but for people who are at-risk for contracting HIV. “I get great smoking cessation from my transgender clients when I start them on hormones,” she said, adding that gender-affirming approaches work very well in primary prevention activities. She further encouraged HIV programs to work with, and train, hormone providers, as they could prove to be very effective referral sources for HIV programs. Hormone providers, she said, have an established “patient base.”

A male-to-female participant said she was forced to identify herself as a man, based on the legal documentation of her gender, in order to receive CARE Act services. Another pointed out that some states do have laws requiring individuals to report what is on their driver’s licenses, leaving no room for self-identification.

To clarify, one of the Project Officers stated that HRSA’s policy allows all CARE Act clients to self identify. However, as the Division Director added, state law supersedes Federal law, and states can apply additional regulations as long as they do not contradict Federal law.

In response to receiving this information, the participant from Houston suggested that HRSA recommend that its grantees ask two questions on intake and other healthcare or eligibility forms:

- What was your gender at birth?
- What is your gender currently?

It was further recommended that HRSA could, and should, require its grantees to provide gender-neutral restrooms at their sites. Such facilities would help create a welcoming and affirming atmosphere for transgender clients.

The participant from CT spoke about the lack of awareness in the gay community regarding transgender issues, and the assumption that queer-focused organizations don't need training to provide services to transgender populations. "A lot of straight trans men don't identify as trans," he said, as a way of illustrating the diversity of the transgender population, their experiences, and their needs.

The participant from Reno, NV noted that there had been little discussion about the side effects of hormone use. These can be diabetes and high cholesterol level, of which many HIV doctors are unaware as possible side effects to hormone therapy. They assume this is a primary care issue and, therefore, do not treat or do not have the resources to treat, she said. The participant from MI suggested that if an outcome of the meeting was the development of standards around hormones, then HRSA should refer to other guidelines besides the Harry Benjamin International Gender Dysphoria Association (HBIGDA) Guidelines. He said that while they filled a need at the time they were developed, he was concerned that they included nothing about informed consent. The physician clarified that the HBIGDA guidelines recommend when to provide hormones, but do not offer guidance on how to provide them.

The Facilitator added that guidelines developed by the Callen-Lorde Community Health Center in New York City, or those developed by Dr. Lori Kohler, Director of the Family Health Center at San Francisco General Hospital, would be more appropriate.

One of the participants stressed the importance of accurate data, and lauded HRSA for including transgender as a population category in the CADR. He further thanked them for providing generous guidelines on the classification of transgender people, but expressed disappointment that they provided no guidance on risk factors. "If I am a female-to-male transgender with a vagina who only has sex with men, am I heterosexual, homosexual, or something else?" he asked. "When I talk to my local provider and my local ADAP, they tell me they don't serve transgender clients, so I think grantees need guidance on this," he said.

The participant from New York, NY, also a provider, spoke on behalf of her clients: Asian and Pacific Islander women who come to the U.S. to make money through the sex trade. She discussed the difficulty in reaching out to a diverse group with so many cultures and languages. She said funding for translation services would be very beneficial. (Translation services are part of creating access, which is what the CARE Act is all about. Thus, translation services are an allowable service under the CARE Act).

Some participants also stated that it's hard to assess what is and isn't credible in terms of information that is on the Internet. A HRSA-sponsored web site with protocols and information would be helpful, they said.

As the conversation began to draw to a close, the Puerto Rican participant asked the group to be really thoughtful about their comments and requests. She said that while hormone therapy is a big concern for many transgender individuals, she is very concerned about the lack of data regarding potential interactions between HIV medications and hormones.

***Living as a man made me feel like I didn't want to live; my life felt broken. Living as a woman has given me hope, and freed me from a lot of the depression I felt for so many years.***

The participant from Washington, DC, said she wanted to be able to tell her community that HRSA and CDC were taking action to address transgender needs. All participants expressed a deep desire to see action on their recommendations, and a plan from HRSA outlining how they will address transgender concerns through their CARE Act programs. Many emphasized that the impact of HIV on transgender populations should be classified as "an emergency."

One of the Project Officers said that HRSA could incorporate transgender issues into grantee guidances for CARE Act funding applications, and would use the information provided by the group to develop some technical assistance interventions to increase awareness of transgender needs among CARE Act providers. She promised that HAB would do as much as possible within the constraints of the current laws and political climate in Washington.

The DCBP Director committed to:

- 1) Produce a report from the meeting;
- 2) Distribute the report among Title III and IV grantees and programs; and
- 3) Share the report and meeting outcomes with Title I and II program staff at HRSA, and explore next-step activities.

A DCBP project officer relayed her experience in arranging for technical assistance to a Title III clinic that would not serve transgender clients. She has let the grantee know that she will continue to monitor the program to ensure that it provides services to transgender clients.

The DCBP Branch Chief for the Southern Region said she would talk to her Title I counterpart in the Bureau about transgender individuals not being allowed to self-identify in Houston. If the issue is not law-related, it will be corrected.

The participants thanked HAB for convening the meeting and said it was truly encouraging to be asked for their input. The participant from Youngstown, OH, said it meant a lot to be heard as a transgender person. Others who expressed initial reluctance about attending said that it was both worthwhile and educational.

In closing, the DCBP Director thanked attendees for their time and energy, and lauded the level of expertise and leadership they possessed. He asked if they'd be willing to share that expertise as HRSA grant reviewers, which would give them an additional opportunity to share the needs and concerns of transgender populations. He urged them to apply online at the HRSA Web site (<https://grants.hrsa.gov/webReview>) or email DCBP if they were interested in becoming reviewers. As a final comment, he told the participants "Don't ever give up. It might be frustrating, but don't ever give up, because consistency is the answer to making things change."

With that, the Facilitator ended the meeting. The group thanked him for his facilitation and his ability to help them provide valuable input to HRSA.