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Table of Contents

Chapter I: Concept Guide	
Introduction	1
The Problems	1
Strategies for Addressing these Problems	2
Guiding Principles	3
Community Mobilization Highlight	3
List of Services Available through CATCH	4
Chapter II: Coalition Guide	6
Phase I: Mobilizing the Community	6
Step I: Identify Groups	6
Step II: Community Preparation Inventory	10
Step III: Next Step for Coalition Development	10
Step IV: Culturally Inclusive Recruitment Strategies	12
Step V: Letter of Invitation	13
Step VI: Formalize a Local Coalition	13
Step VII: Coalition Structure	13
Community Mobilization Highlight	14
Phase II: Creating a Community-Driven Resource Inventory	15
Step I: Creating a Coalition-Driven Needs Assessment	15
A: Data Collection Recommendations	15
B: Elements of a Needs Assessment Process	155
Phase III: Conducting a Gap Analysis	17
Phase IV: Identifying Priorities	17

	Phase V: Creating Strategies	17
	Step I: Guiding Questions	17
	Step II: Identifying Strategies	18
F	Phase VI: Ongoing Evaluation	19
	Community Profile Spreadsheet: Attachment A	20
	Attachment B: Example Letter of Invitation	21
	Attachment C: Meeting Agenda Template	22
	Attachment D: Example of Bylaws	23
	Attachment E: Example Resource Inventory Methodology & Questionnaire Template	27
	Attachment F: Data Collection Recommendations	28
	Attachment G: Summary of Findings	30
	Attachment H: Example of an Evaluation	63
	Attachment I: Example of a Coalition-Driven Needs Assessment	65

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CHAPTER I: CONCEPT GUIDE

Introduction

- The goal of CATCH is to increase the capacity of communities to plan, implement, and evaluate comprehensive, community-based health promotion programs targeted toward transgender health.
- In addition, CATCH is designed to strengthen transgender community access to and utilization of HIV prevention services and health care by implementing the Coalitions in Action for Transgender Community Health community mobilization model.

The Coalitions in Action for Transgender Community Health (CATCH) project brings communities together with a shared vision for healthy change. In community mobilization, cultural sensitivity and awareness are interwoven into the fabric of change because the community is the driving force. Community driven change can be complex, challenging and overwhelming, so CATCH brings together academic research, local coalitions and health departments in order to support the process. It encourages the use of local expertise instead of having to seek outside expertise for every step the coalition hopes to achieve. CATCH conserves valuable resources by guiding the selection of strategies that are most likely to be successful. It is an efficient, inexpensive and easy to use tool. Most of all, it's a fun and empowering model that helps individuals, coalitions, and local experts to increase their capacity to advocate for transgender community health and discover strategic solutions to address complex issues. CATCH is adapted in part from the *Planned Approach to Community Health (PATCH)* developed by the CDC and partners. Additionally, some content has been incorporated and adapted from the *Community Readiness Model*.

THE PROBLEMS

Recent studies have identified many structural barriers to HIV prevention services and health care for transgender people including the lack of:

- · skilled providers,
- accurate transgender data collection,
- and funding for transgender-specific HIV prevention programs.

According to a study done in Boston (Sperger, et al., 2005)³, discrimination in the provision of trans-inclusive health care services, and "blatant rejection" of trans people were found to be the norm. The National Center for Transgender Equality conducted a national survey in 2011 which identified barriers that exist for transgender and gender-variant people. The outcomes of their survey show the appalling effects of social and economic marginalization, including much higher

¹U.S. Department of Health and Human Services. *Planned Approach to Community Health: Guide for the Local Coordinator.* Atlanta, GA: U.S. Department of Health and Human Services, Department of Health and Human Services, Centers for Disease Control and Prevention National Center for Chronic Disease Prevention and Health Promotion.

² Plested, B.A., Edwards, R.W., & Jumper-Thurman, P. (2006, April). *Community Readiness: A handbook for successful change.* Fort Collins, CO: Tri-Ethnic Center for Prevention Research.

³ Sperber, J., Landers, S. & Lawrence, S. (2005). Access to health care for transgender persons: Results of a needs assessment in Boston. International Journal of Transgenderism, 8(2), 75-91. Doi:10.1300/j485v08n02_08

rates of HIV infection, smoking, drug and alcohol use, and blatant discrimination by health care providers against transgender people⁴.

- **Refusal of care:** 19% of 6,450 trans identified and gender non-conforming individuals from throughout the United States reported that they were refused medical care due to their transgender or gender non-conforming status, with even higher numbers among trans people of color in the survey.
- **Uninformed doctors:** 50% reported having to teach their medical providers about transgender care.
- **High HIV Rates:** Respondents reported over four times the national average of HIV infection, with rates higher among transgender people of color.
- **Postponed care:** Survey participants reported that when they were sick or injured, they postponed medical care due to discrimination (28%) or inability to afford it (48%).
- **Violence and Harassment:** Over one-quarter of respondents (28%) reported verbal harassment in a doctor's office, emergency room or other medical setting and 2% of the respondents reported being physically attacked in a doctor's office.

The National Academy of Sciences recently released a report that highlights some barriers to accessing transgender health care⁵. Their findings suggest that a lack of provider training and a bad reputation due to that lack of competence.

STRATEGIES FOR ADDRESSING THESE PROBLEMS

In order to address these barriers, the Center of Excellence for Transgender Health (CoE) has been engaged in highly successful community mobilization efforts for transgender communities in California since 2007. We have been developing and testing components of our community mobilization model for HIV prevention in at-risk transgender communities by building research, leadership, and capacity-building experience, and disseminating cutting-edge information on transgender HIV prevention via our state-of-the-art website (www.transhealth.ucsf.edu) and through the networks we have developed regionally. By organizing local "Town Halls" throughout California in partnership with the CoE Community Advisory Board (CAB), the CoE has been able to build local coalitions that promote provider networking and community utilization of existing services. In the CATCH Model, the coalition guides the community mobilization process and leads data collection and analysis efforts, prioritizes prevention needs, develops a comprehensive plan to strengthen community access to and utilization of HIV prevention services, and decides how to evaluate these efforts. Materials designed to help a local coordinator facilitate implementing CATCH are provided in this toolkit. These materials provide detailed, step by step information on the process to follow and issues to consider when utilizing CATCH for local transgender communities.

⁴ Grant, Jaime M., Lisa A. Mottet, Justin Tanis, Jack Harrison, Jody L. Herman, and Mara Keisling. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey.* Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force. 2011.

⁵ The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding http://www.nap.edu/catalog.php?record_id=13128 SUMMARY 3 particularly gay and bisexual men,

⁶ Local coordinator – A community member who has taken the lead in mobilizing and establishing a coalition.

GUIDING PRINCIPLES

- 1. Transgender community members participate in the process by developing coalitions with providers and others invested in community mobilization.

 Fundamental to CATCH is active participation by a wide range of community members, along with providers and other stakeholders. A local coordinator facilitates meetings and manages day-to-day activities, but the coalition drives the process as it gathers and analyzes community data, sets priorities, plans intervention activities, makes decisions on the community's HIV prevention priorities, and disseminates information about the community mobilization activities to local communities.
- **2.** *Data drives the priorities set by the coalitions.* Many types of data to describe the transgender community's health status are gathered and reviewed, and help in setting priorities.
- 3. Coalitions develop a comprehensive strategy to increase access to and utilization of HIV prevention services, including testing. Community members analyze the service gaps and barriers that contribute to high rates of HIV and low utilization of services in transgender communities, especially among transgender women of color.
- **4.** *Evaluation emphasizes feedback and program improvement.* Timely feedback is essential to the success of coalitions and is incorporated continuously to make improvements and ensure active and diverse participation by the community in the mobilization project.
- **5.** *The community capacity for health promotion is increased.* The CATCH process is designed to respond to feedback from the community and can be repeated to address various priorities. The CATCH Model aims to increase the capacity of community members.

The guiding principles related to community participation and capacity building are essential to ensure community ownership. Although the local coordinator facilitates the program, the community directs the program, and the program belongs to community members. Their decisions determine how the program progresses. All participants in the CATCH process share in its success.

COMMUNITY MOBILIZATION HIGHLIGHT: NEW MEXICO

In Albuquerque, New Mexico the coalition building process began through collaborations between local community leaders, trans allies, the state health department, local community based organizations and with support from CATCH beginning in 2010. In the spring of 2011 the New Mexico Department of Public Health held its second New Mexico Transgender Summit. As a result of networking through both summits, "The New Mexico Transgender Coalition" has emerged. The coalition is made up of approximately 20 community members interested in establishing a formal coalition with goals to increase access to comprehensive, culturally appropriate, trans-inclusive health care and HIV prevention services.

LIST OF SERVICES AVAILABLE THROUGH CATCH:

Here is what your community can expect when partnering with the CoE to implement CATCH.

• COMMUNITY PREPARATION INVENTORY

 The community mobilization specialist will walk your community through the process of evaluating the progress made thus far, and in turn will provide those interested in forming a coalition with an objective analysis of the progress made thus far.

• PROCESS AND OUTCOME MONITORING OF COALITIONS

- Resources such as process evaluation tools, ongoing technical assistance, and capacity building assistance regarding process monitoring.
- o Outcome monitoring will be provided.

• COALITION BUILDING

- o Assist interested community members, department of public health, and other agencies and organizations to establish a coalition.
 - Recruitment Strategies
 - Leadership Development
 - Partnership Development
 - Resource Development
 - Mission, Vision and Bylaws Development
 - Cultural Inclusivity Development

• COALITION DRIVEN RESOURCE INVENTORY

- Assist coalitions in developing a method for finding local resources available for the transgender community in your area.
 - Resource Inventory Tool Development
 - Transgender Resource Identification Methods
 - Strategies for Presenting Inventory Findings

• COALITION DRIVEN NEEDS ASSESSMENT

- Assist coalitions in developing a needs assessment that incorporates best practices and transgender data collection methodology.
 - Cultural Inclusivity Strategies
 - Identification of Most Effective Needs Assessment Methodology
 - Internal Review Board Process Support (if interested in publishing findings)
 - Transgender Specific Data Collection Recommendations
 - Outreach Strategies

• COALITION DRIVEN GAP ANALYSIS

- Assist coalitions in the process of identifying gaps in local trans-inclusive services in the local community.
 - Recommendations for Data Analysis
 - Recommendations for Reporting Findings

• IDENTIFICATION OF PRIORITIZED NEEDS

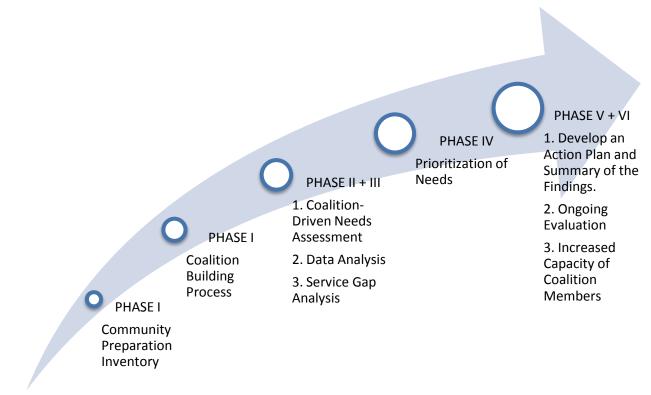
- Guide coalitions through a process of prioritizing the community identified needs.
 - Facilitation of Prioritization Process
 - Process Evaluation

• COMMUNITY DRIVEN STRATEGIC PLAN

- Assist coalitions in the process of developing a strategic plan based on the prioritized needs, capacity, expertise and best practices.
 - Provide Ongoing Technical Assistance
 - Review of Strategic Plan and Feedback
 - Present Findings and Outcomes on the Center of Excellence for Transgender Health Website

These processes are explained further in the next chapter.

CHAPTER II: COALITION GUIDE



This graph is a visual representation of the six phases of CATCH. The phases of CATCH are meant to be fluid and can be revisited at any time. This visual representation points out the likely process that a community would go through when utilizing the CATCH community mobilization model.

PHASE I: MOBILIZING THE COMMUNITY

Throughout the United States there are various community mobilization models being used. Although these efforts can result in positive changes, they're more often than not based on grassroots efforts which can be difficult to sustain. In order to effectively create sustainable change there must be collaborations in place that are often difficult to establish due to structural barriers such as transphobia. Transphobia is a term which describes discrimination against gender non-conforming and gender-variant people, based on the expression of their internal gender identity. In some cases, persistent lack of knowledge about trans and gender variant people also amounts to transphobia. CATCH provides a framework for community health planning for everyone involved through a collaborative and community mobilization model that helps overcome transphobia.

STEP I: IDENTIFY GROUPS

The public perception is that the transgender community is homogenous when in reality it is as diverse as any other community. Gender identities, gender expressions, sexual orientations, socioeconomic status and ethnicities vary widely. When identifying potential coalition members, it's important to keep in mind that it's critical to invite individuals that represent a cross section of the community as well as allies and partners. This will ensure that future efforts of coalitions are as inclusive as possible of the rich diversity of our communities.

No matter how the community is defined, residents have public health needs in common and must have the resources within the community to respond effectively. To ensure that these internal resources are present, the community effort must include high-risk population that may become a target of future interventions. Members of a community should also have a "sense of community." As we work to unite the community, one task may be to help community members increase their sense of the larger community. It will be useful to establish a general definition of community before beginning to mobilize community members and form partnerships, adjusting the definition as appropriate. In essence, the community defines itself. The community begins to be defined when a group of citizens comes together to improve community health, and the CATCH process can accelerate this.

Community momentum can be strong when we all feel the devastating impacts of the barriers that exist for the trans community such as the high rates of HIV infection in transwomen. CATCH can be used to reduce the rates of HIV infection by promoting healthy and empowering coalitions made up of at risk trans people. Other similar community mobilization efforts have worked in various regions, for example:

- In October 1999, the Centers for Disease Control and Prevention (CDC), in collaboration with federal, state, and local partners, launched a national plan to eliminate syphilis. In the plan, CDC identified key strategies needed for elimination. Through mobilization, communities made syphilis education a part of community health programs, developed efforts to reach at-risk populations, and increased awareness in policy makers and community leaders regarding the importance of eliminating syphilis from their communities. This effort promoted increased syphilis screenings and reporting of results by health care providers.⁷
- The CAN program was established in September 2000 to bring together local organizations, businesses, social clubs, and churches that served the men's community to focus attention on the HIV prevention needs in their community. Additionally, CAN worked with individual establishments to assist them in the creation of their own HIV prevention programs and activities specific for their own clients, members and congregates. This allowed for creative planning and new ideas, which ranged from bookmarks with prevention messages on them given out at local bookstores, to bartenders trained to convey prevention messages while serving drinks. It also include a postcard campaign sponsored jointly by several local shops, that have focused prevention messages for different groups within the men's community; or an erotica reading and safe sex workshop at a local leather boutique. The goal of CAN was to mobilize the community to become directly involved in designing, implementing and maintaining its own on-going HIV prevention campaign, while reinforcing a culture of awareness and prevention in the men's community.

Mobilizing the community is an ongoing process that involves identifying or developing the organizational structure capable of carrying out the change, and managing the long-term efforts to

7

⁷ http://www.cdc.gov/std/see/Community/CommunityGuide.pdf

⁸ http://www.noaidstaskforce.com/can

keep members and the community informed and energized. To gain the level of involvement necessary for a successful program, local coordinators should work with community members to:

- Define and describe your community as centered on a particular health-related issue.
- Gain and maintain commitments from key organizations and individuals within and beyond the community.
- Identify and create links to community resources.
- Determine the readiness level for community mobilization and communicate with the community often and through multiple channels.
- Form partnerships for resources and support within and beyond the community.
- Establish the structures and procedures needed to manage CATCH effectively.

During recruitment it's imperative to tap into existing groups so that there's some establishment of multiple perspectives to move forward in an effective and coordinated manner. The following is a list of existing groups that may be helpful:

• Community HIV Prevention Planning Groups

Most local health departments receiving funding for HIV prevention from the Centers for Disease Control and Prevention (CDC) are required to have an HIV Community Planning Group (CPG). HIV prevention community planning is a collaborative process by which the health department can work in partnership with the community to implement a CPG to develop a comprehensive HIV prevention plan that best represents the needs of populations infected with or at risk for HIV.

• Agency Advisory Boards

An Advisory Board is a collection of individuals who bring unique knowledge and skills which complement the knowledge and skills of the formal Board members in order to more effectively govern the organization. Also, Advisory Boards are sometimes used to maintain formal and visible relationships with people who have particular strong status, for example, people whose terms have expired on the governing Board, leaders in the community and people with highly respected skills in certain program areas.

• City, County, and Other Government Officials

Most health departments have many individuals tasked with being community liaisons. These individuals have expertise in working within the complex structures of government agencies like local health departments, legislative bodies, and other aspects of government.

Government Commissions

Most county or city governments have commissions made up of community members that represent various districts, communities and/or expertise. Human Relations Commissions are usually receptive to public comment during their regularly scheduled meetings. Commissions collect, document, investigate and create action steps that they in turn recommend to their government representative. In order to find these groups we recommend looking at the city and county websites. These commissions are there for community to bring issues to the table that they can in turn report to local government officials.

• HIV Planning Councils

HIV Health Services Planning Councils consist of volunteers from throughout different regions within a county or throughout several counties and is mandated by the U.S. Congress to determine the size and demographics of the population of individuals with HIV.

Transgender Groups

Many regions throughout the country have established groups of trans identified individuals that are interested in advocating for trans civil rights and have other shared interests. Usually there are peer support groups, and other more social groups that can be found by word of mouth or by searching the internet for local resources.

Partners, Spouses, Allies and Families of Trans People

Many trans and gender-variant people have partners, spouses, families and friends that are more than willing to stand up and fight for civil rights because of the tragedies they've witnessed their loved ones experiencing. It's really tough to understand what it's really like to be transgender or gender non-conforming until you walk through life with a trans person. Partners, relatives and friends get firsthand experience and often have the drive to end the discrimination and systemic barriers that exist for trans people in today's society. Oftentimes trans-people don't have family support, but in some fortunate families there is support that can be tapped into for coalition building through a simple invitation to participate.

Health Organizations

Many health organizations are interested in responding to trans healthcare needs made more visible by health disparities such as high rates of HIV among trans people. These health organizations may have strong networks with medical providers, other agencies and community planning groups. There's usually interest in a developing volunteer pools made up of community members.

• Faith Based Organizations

Another possibility for community engagement is to reach out to faith-based organizations. Many churches and religious organizations are trans welcoming and sponsor social groups and/or peer support groups. It's also becoming increasingly common for religious leaders to be trans-identified. In the past trans people were frequently rejected by religious organizations, but times are changing, and more religious organizations are welcoming. Some religious organizations that tend to be queer friendly are: The Universal Fellowship of Metropolitan Community Churches, LGBT Jewish Synagogues & Organizations, and the Gay Christian Network. More resources are available online for further research.

Medical Groups

In practically every city and town there are managed care facilities. For example, Kaiser Permanente is known for having facilities throughout the West coast and in the Mid-Atlantic region. These medical centers have a broad spectrum of medical services under one central location. Medical groups usually have a vast array of committees tasked with getting community input on what services are necessary. Including people from these committees in the coalition building process can prove to be very fruitful.

STEP II: COMMUNITY PREPARATION INVENTORY

The Community Preparation Inventory (CPI) is an innovative method for assessing the level of readiness of a community to develop and form a coalition. It can be used as both a research tool to assess distribution of levels of readiness across a group of communities or as a tool to guide community mobilization efforts at the individual and community level. The CPI can be completed via telephone interview or whatever method is most convenient for participants. During the interview process the Community Mobilization Specialist will guide the interviewee through a set of questions that will take from 20 to 45 minutes. The Community Mobilization Specialist can then identify which phase of CATCH the community is currently in. This is critical to the success of community coalitions because it identifies strengths in communities and opportunities for growth. Communities and/or individuals can request capacity building assistance (CBA) and/or technical assistance (TA) during any phase of CATCH. The CATCH project can offer each community the very best level of expertise according to the results of the assessment. The diagram below illustrates how the process works.



This process is designed to help CATCH support your community mobilization efforts in a respectful way that will save your community precious resources in the long run. The CPI will also help CATCH develop an individualized tool kit for your community's efforts.

STEP III: NEXT STEP FOR COALITION DEVELOPMENT

Once the CPI has been completed, the next step for building a coalition is to take a closer look at the communities represented within the coalition. This can be accomplished through a coalition profile. An example coalition profile is included as **attachment A** in this toolkit. Basic demographic information may help ensure that the makeup of the coalition reflects the makeup of the community. A coalition profile can help you decide how best to approach your community and its health problems as well as identify potential obstacles to communication.

The example of the coalition profile is only a suggestion which can be adapted. Coalition members should know that this information will be solely based on a self reporting basis, and may include personal information that individual coalition members may not wish to disclose. This is simply a

tool to help the local coordinator(s) as well as (if applicable) the executive committee (a coalitionelected group of representatives that have the capacity to lead efforts as well as provide ongoing guidance.) plan recruitment efforts.

CATCH can be implemented by community based organizations, government agencies, and community members. An important consideration is the availability of resources, energy and commitment from community members, agencies and/or other key stakeholders. Identify existing community groups and consider whether an existing group could undertake the CATCH process or provide a foundation for building a structure for carrying out CATCH. If existing community groups are not appropriate, a new community group will need to be formed. Before the first community group meeting in Phase I is scheduled, commitments should be agreed upon that include the following:

- A lead agency or existing community group to sponsor the process
- Time for the local coordinator to facilitate the process
- Three or more agencies or organizations to provide support and resources
- Support from key leaders, local champions*, and political stewards*
- Broad-based membership on the community group and steering committee
- Collaborations and partnerships *within* the community
- Collaborations and partnerships *beyond* the community
- Time required to develop a community-based strategy

Identify a lead agency to sponsor the process in the community. The lead agency could be the local health department, a community hospital, a university, a faith based community center, or other agency. If there is a local health department and it is not the lead agency, they should be encouraged to participate because of their key role in the health and well-being of the community. The lead agency should clarify what resources it brings to CATCH.

The amount of your time required to manage CATCH depends on the help and resources available, community traditions with regard to volunteerism, and the partnerships that are established. Most of the information in this chapter will assist you in gaining commitments and establishing the structure needed to manage CATCH effectively.

Local coordinators from existing coalitions have found that identifying and recruiting "program champions" proves invaluable. Those individuals can serve as "ambassadors" for the program to get things done. These program champions may serve two different roles: local champion and political steward. The **local champion** consistently advocates for the program. Although the local coordinator also helps perform this function, ideally the local champion takes the lead on developing any local contacts thus freeing the coordinator to manage day-to-day activities of the coalition. The **political steward** steers the coalition through the political red tape, adds credibility to the program, and helps obtain resources. You may find it helpful to recruit program champions within the lead agency and within other community organizations, including local government, as appropriate.

The lead agency, program champions, and local coordinator should hold orientation meetings and one-on-one discussions with key people to gain commitments of support from at least three other agencies or groups in the community. These commitments should include letters that specify the nature of the support. Some examples of support are:

- participation in meetings
- assistance with training and skill-building activities
- staff time
- meeting space
- clerical support
- copying services
- mailing services
- supplies
- funds, or other resources

STEP IV: CULTURALLY INCLUSIVE RECRUITMENT STRATEGIES

It's sometimes difficult to stretch beyond our cultural limitations because of discomfort or fear. Although these are valid feelings, culturally inclusive recruitment strategies ask us to step outside of our comfort zones. Well-meaning agencies often say that they're providing services for specific populations and later realize that it's more difficult than initially thought to reach populations that are underserved, underrepresented and disenfranchised. Exclusion of diversity is usually a capitulation to the idea that there aren't enough people in a certain population to be represented at the planning table. This misconception should be eliminated, and efforts should be focused on solutions such as:

- Creating marketing materials, fliers, palm cards and other recruitment materials in languages that are reflective of the populations being recruited.
- Visiting events like drag shows, fundraisers for the trans community, balls, and making an effort to connect with people that are there participating. Usually there are leaders of events that can be seen as community leaders by people participating in these events.
- Remaining open to different cultural perspectives and ideas.
- Creating an environment that has space for diversity.

Once community members are identified, supporting the outreach efforts of the persons recruiting specific cultures is paramount.

STEP V: LETTER OF INVITATION

To support your efforts to bring individuals and groups together and build your coalition, CATCH has created an example letter (see **attachment B**) This which may be adapted as needed. Before preparing the letter there are several things to consider and include within the invitation.

- Establish a location for the meeting to take place. This can be your home, an agency or a restaurant, etc...
- Nail down an accessible time for community participation.
- Estimate how much time it will take to have the meeting, and discuss what commitments people will need to make in order to create a sustainable coalition.
- What is the reason for the call to action?
- Why is it important to have this meeting?
- When will the meeting take place?
- Where will the meeting be held?
- How did this come about?
- Is there anyone else involved in the coordination effort, providing space, food, resources?

Once all of this information is solidified, the letter of invitation can be sent out electronically (least expensive and quickest method), handed out, or mailed (to reach people that may not have internet access). Congratulations! The coalition building process has begun!

STEP VI: FORMALIZE A LOCAL COALITION

Now that the invitation has gone out, it's time to think about the meeting itself. Agenda-driven meetings often provide a good vehicle for inspiring conversation around different topics, but in some instances agendas can seem off-putting. We recommend using an agenda as a springboard for discussion for this initial gathering of like minds. You'll find an example of an agenda as **attachment C**.

The framing or tone of the first meeting will set the pace and tone of the coalition. CATCH is a community driven community mobilization model, so it may be more appropriate to create the agenda along with the participants. Of course, you must have some general ideas to start from, but remaining open to feedback is essential to the coalition building process.

STEP VII: COALITION STRUCTURE

During the first meeting it would be very helpful to ask several questions:

- How would we like to structure the coalition?
- Should we have a formal process with bylaws?
- Do we need to have different working groups?
- Should we formalize an executive committee?
- Is it necessary to have a minute taker?
- Where can we store all of the information we discuss?
- Is it necessary to keep information discussed available for community to have access to it?
- Should we come up with a name for our coalition?

• How do we get more people involved?

We recommend a structured coalition since the phases of CATCH are somewhat complex in nature. In order to be able to get the amount of work done that's ahead, structure will be critical. You'll find an example of bylaws and some resources for developing them as **attachment D**. The example is provided for coalitions, but it's best to develop bylaws specific to your coalition needs, mission, vision and goals.

COMMUNITY MOBILIZATION HIGHLIGHT: BALTIMORE

Regardless of what structure is decided upon, state health departments have proven to be a reliable and an invaluable resource in identifying existing coalitions throughout the country. Frequently state health departments have already begun task forces or coalitions to help inform their funding and programmatic efforts. The state health department may also be able to point you toward other resources or agencies. Following is an example:

In 2007 the Sexual Minorities Program Manager of the Maryland Department of Health and Mental Hygiene, Infectious Disease and Environmental Health Administration Center for HIV Prevention, Jean-Michel Brevelle coordinated an effort to ultimately reduce the rate of HIV infection among transgender populations through reducing stigma and oppression as well as improving access to health and human services. This effort was dubbed "The Transgender Health Forum" and was held at a local university in the form of a day-long program.

During that day three separate meetings were held which were geared toward gathering information that would provide the state with critical consumer information that could potentially impact programmatic and funding priorities. All three meetings had the same focus of identifying comprehensive lists of health and human needs, prioritization of those needs, and finally creating community driven action items based on that information. The first meeting was specifically for transgender and gender-variant individuals, the second was for health and human services providers, and the third meeting brought both trans people and providers together.

Through this strategic process, the state of Maryland along with key stakeholders was able to:

- Identify immediate needs of transgender consumers.
- Identify existing trans-inclusive programs.
- Compare the needs and available resources.
- Identify gaps in services.
- Prioritize identified needs and gaps in existing services.
- Develop a community-driven strategic plan.
- Create a community-driven coalition.

PHASE II: CREATING A COMMUNITY-DRIVEN RESOURCE INVENTORY

A resource inventory will provide you with a clear picture of resources available in your community. An example of a resource inventory is included as **attachment E.** This can be used as a template for any local efforts. Also, **attachment G** has a sample list of questions that were used for a resource inventory throughout the state of California.

STEP I: CREATING A COALITION-DRIVEN NEEDS ASSESSMENT

Conducting needs assessments can seem like a daunting task. However, one of the best ways to make people feel valued is to ask their opinion. A needs assessment gives people an opportunity to weigh in on their own experiences, and provide critical information that will eventually provide clear goals for the coalition. Conducting needs assessment can help support collaborative planning, identify resources, and revitalize local momentum through an organized coalition driven process. The needs assessment will also inform prioritization of needs, strategic planning and advocacy efforts.

A: DATA COLLECTION RECOMMENDATIONS

The goal of a needs assessment is to gather information accurately in order to understand, compare, report, and apply it to enhancing and improving services, or inspire new efforts. You'll find data collection recommendations put forth by the Center of Excellence for Transgender Health as **attachment F.**

B: ELEMENTS OF THE NEEDS ASSESSMENT PROCESS

- Creation of the needs assessment
- Collection and analysis of data
- Survey information
- Focus or discussion groups
- A public policy review
- A review of current programs, activities and resources

This information is necessary for short and long term success. Although it may be challenging to collect this information, it's best to collect as much as possible.

Collect existing data:

Health departments, community-based organizations and other agencies sometimes have recent data from their own efforts. This information can serve as a starting point for your efforts. Transgender specific data can sometimes be found in HIV surveillance data collection and behavioral health programs.

Conduct a public policy review:

Information on laws is available through most public libraries. Local laws can impact transgender community members in many ways. Perhaps there is already a law or statute in place that hasn't been enforced effectively. It could also be that more resources are needed in order for laws, statutes, or regulations to be adequately implemented.

Conduct focus groups with key stakeholders:

Data and numbers are very important to the success of a needs assessment, but it's also essential to include the reasons "why" things may be the way they are. A focus group is a fairly simple way to gather this critical information through eliciting comments, opinions and perceptions about a particular problem or need.

AN EXAMPLE OF A FOCUS GROUP

A focus group can be conducted as simply as the following method (a tape or digital recording device is recommended to ensure complete data capture):

Introductions and warm up.

- Introduce yourself and your assistant or co-moderator.
- Ask each participant to introduce themselves by first name only.

Explain the purpose and ground rules of the focus group.

- Explain why group members have been asked to participate, i.e., to learn their views and
 - opinions on local services available (or lack thereof) for transgender community members, and to obtain their suggestions for solutions.
- Explain the ground rules, including:
 - o Only one person should speak at a time.
 - o Every opinion and comment has value.
 - o Everyone in the group is encouraged to participate.
 - o People should remain quiet when others are offering their views.
- Explain that the session is being audio taped so it can be analyzed later.
- Remember to tell participants that they will not be identified by their full name and their
 - business or organizational affiliation will not be identified in the official record. All responses in a focus group are anonymous.

Develop a list of questions of relevant questions you would like answered.

- With each question, you should develop a list of probes. Probes are designed to prompt
 people to answer if they are having trouble getting started or can't think of any
 responses. For instance, your question may be: "Is access to health care a serious
 problem in your
 - community?" If no one answers, an appropriate probe may be "Has there been a complaint in your community about local health care services being insufficient for transgender people?"

The Coe is available to you as a resource for recommendations, technical assistance in the creation of needs assessment, focus groups, or capacity-building assistance regarding this process. An example of a coalition-driven needs assessment is included as **attachment I.**

PHASE III: CONDUCTING A GAP ANALYSIS

Now that local resources have been identified, it's time to see where the gaps in services are. This is a fairly simple process of comparing the identified needs to the resources available in your community that were identified in the resource inventory. All of the needs that do not have a resource able to meet those needs are part of the "gaps" in services. Once identified the next step is to prioritize the needs that will fill these gaps.

PHASE IV: IDENTIFYING PRIORITIES

Prioritization is a very important process that helps coalitions to better understand which needs are critical and which are achievable. In order to facilitate change, coalitions will need to prioritize the identified needs. There are many ways to accomplish this, but it's always best to keep this step simple. The table below shows one process that can be helpful. Coalition members can vote in order to rank needs:

Identified Need	Urgency 5=high 3=moderate 1=low	Feasibility 5=high 3=moderate 1=low	Commitment 5=high 3=moderate 1=low	Impact 5=high 3=moderate 1=low	Total Points	Priority Ranking
Ex: HIV testing	5	4	4	5	18	2
Homelessness	3	4	4	4	15	3
Health Care	5	5	4	5	19	1
				·		

You can find other methods for prioritizing needs on the internet by simply entering "strategies for prioritizing needs" in any web-based search engine.

PHASE V: CREATING STRATEGIES

Brainstorming strategies can be a way to gather ideas from members of the coalition. Simply put up some newsprint or chart pad sheets with one of the prioritized needs written at the top of each sheet. Ask participants to brainstorm on each one to develop possible strategies to address that need. One important guideline for this process is that no idea is wrong or right; all ideas should be transcribed to keep the momentum going. Don't stop to discuss whether an idea will work; Just keep generating ideas. Once all of the ideas are noted for all to see, review them as a group using the following questions.

STEP I: GUIDING QUESTIONS:

- What goal(s) are we hoping to accomplish?
- What would we like to happen, or what objectives will come about as a result? (objectives)
- How will we know when we've accomplished it?
- Where, when and with who do we want to work?
- Where will it work?
- What obstacles do we face?
- What resources, including financial, do we have?
- What resources do we need?
- What are the first steps, following steps, and activities?

STEP II: IDENTIFYING STRATEGIES

Once the brainstorming process is complete, it's time to decide on some strategies to achieve your goals and objectives. A goal is what the coalition hopes to see as a result of the strategy, and an objective is what specific outcomes will take place because of the strategy. Furthermore, objectives are measurable outcomes that can be evaluated through simple questionnaires that the CoE can help you develop.

Here's an example:

A coalition-driven needs assessment conducted in May of 2012 identified that there is a substantial need for medical providers that understand how to provide competent and culturally sensitive services for transgender patients. In order to achieve the goal of an increased number of comprehensive trans health care providers, the Coalition has come up with the following strategies which include:

- Train all staff.
 - The coalition has knowledgeable facilitators that can deliver trans sensitivity training for local health care providers.
- Supply local health care providers with best practices for the delivery of said health care services.
 - We recommend that all interested clinicians review and integrate the HIV prevention and care services best practices developed by the Center of Excellence for Transgender Health.
 - It is also recommended that clinicians become familiar with and implement the CoE's Primary Care Protocols.

Once the strategies are clearly identified, it's time to share them with local agencies that can benefit from seeing the conclusions and types of recommendations they can implement. Your public health department can more than likely help disseminate the strategies to the agencies they fund, and other service providers can be directly approached by coalition leaders. **Attachment G** is an example of a summary of findings that can serve as a template for your coalition.

PHASE VI: ONGOING EVALUATION

It's essential to get buy in and opinions from coalition members to keep the momentum going for mobilizing as a community. One way to ensure that everyone gets their turn to share and contribute is through ongoing evaluation. The goals of evaluation are to monitor progress, to understand how useful the meetings are and if the group process is working well, and to identify what can be improved and what new steps should be taken. The following list explains why evaluation is so important:

- Provides information for other coalitions to learn from and replicate your efforts.
- Results can be shared on the CoE coalition page to highlight and publicize your coalition.
- Sometimes evaluation can bring forth unintended effects that others can learn from.
- Ongoing evaluation will help your local coalition gain credibility.
- Evaluation may also open the door to funding opportunities available in your area.
- This is also a great way to document what the coalition has done and accomplished.
- Ensures that the coalition reflects a diverse cross section of the population.
- Assesses effectiveness and success and proves that the coalition is making a real difference.

You will find several templates for ongoing evaluation in **attachment H.** Feel free to restructure these templates and use them as a starting point for the development of your own evaluation tools. Through continued evaluation, coalition members will increase their capacity, understand and adopt new ideas to move forward, and further develop the community spirit.

ATTACHMENT A: EXAMPLE COALITION PROFILE SPREADSHEET

Table I: Coalition Membership Matrix

Name	Gender Assigned at Birth	Current Gender Identity	Race/Ethnicity	Age	Region	Employment Status	Type of Employment	Why is the person interested in the coalition? (ie: HIV, health care, social services.)

ATTACHMENT B: EXAMPLE LETTER OF INVITATION

[insert date]

Dear [insert name],

I hope that this letter finds you well! I was referred to you by [insert name of individual] at the [insert agency name here], who recommended you to be a member of the Coalition for the Coalitions in Action for Transgender Community Health (CATCH). CATCH is designed to strengthen transgender community access to and utilization of HIV prevention services and health care by diffusing the Coalitions in Action for Transgender Community Health community mobilization model. A key strategy in CATCH is to encourage linkages within the community and between the community and the state health department, universities, and other regional and national levels of organizations that can provide data, resources, and consultation.

The Coalition needs community direction as we embark on an effort to improve the quality of health for transgender communities throughout the region. An essential part of the Coalition's success will be programmatic guidance from expert individuals within various transgender communities and service providing agencies. Your guidance is essential for the process that will take shape through the formation of a community driven needs assessment, prioritizations of community identified needs, a strategic plan, and dissemination of information about the findings within local communities.

The Coalition will meet [insert frequency of meetings] in person and via quarterly conference calls (as we launch the Coalition we will meet monthly until our first in person meeting).

Please let me know if you are interested in joining our fantastic Coalition! I am available to answer any questions you might have by email [insert email] or by phone at [insert phone number]. I encourage you to look at the Center of Excellence for Transgender Health's website for more information about the work that we do: www.transhealth/catch.ucsf.edu.

I sincerely look forward to working with you!

[Insert name]

Local Coordinator [or insert title]

Transgender Community Coalition [or insert name of Coalition]

ATTACHMENT C: EXAMPLE MEETING AGENDA



Community Meeting Agenda Friday, May 21st, 2010 12:00 pm – 1:30 pm

- I. Introductions and Welcome
- II. Discuss reasons for having the meeting
 - a. Introduce agenda
 - b. Brainstorm additional agenda items
- III. Envisioned Change
 - a. What would be the ideal health care setting for our community?
 - b. How can we get there?
- IV. Logistics
 - a. Where is there space for us to meet?
 - b. What resources or office supplies would be ideal to have access to?
 - c. Who among participants can provide us with space and/or resources?
 - d. When is the best time to meet?
 - e. Should someone take minutes of our meetings?
- V. Feedback
 - a. Did this process work for everyone?
 - b. What did you like about this process?
 - c. What would you do differently?
 - d. How can we make that happen together?
- VI. Next meeting
 - a. Date of next meeting
 - b. Time and location
 - c. Should we have a set agenda again?

ATTACHMENT D: EXAMPLE BYLAWS

Bylaws

The (coalition name) is a body convened to provide guidance and accountability for (name of state or region) and to partner towards increasing access to comprehensive, effective, and affirming healthcare services for transgender and gender variant communities.

Composition

Nomination: Any coalition member may nominate a new member. Applicants may also self-nominate.

Demographics

Effort will be made to recruit applicants who not only fulfill demographic representation, ethnic/racial diversity, gender diversity and other socio-economic factors, but also candidates who will compliment the group as a whole. Special efforts will be made to encourage youth to apply when possible. The coalition will pursue applicants who have knowledge, experience and/or interest in transgender healthcare services among transgender and gender variant communities.

Sharing of designated position Proxy coalition members will not be allowed.

Selection Process

Applicants will provide a letter of intent, and answer a series of questions around work history, advocacy and capacity with transgender healthcare services in their communities. Vice chairs from the executive committee will coordinate recruitment efforts. Advancement of candidacy will occur with a unanimous vote from the executive committee.

Number of Members:

There will be no less than (insert number) members and no more than (insert number) members at any given time.

Governance

Executive Committees

An executive committee will be formed with one chair to advise the functions of the coalition and to oversee functions of the coalition. Two vice chairs will be appointed to provide leadership for coalition working groups, recruitment and retention. Each committee member will lead working groups where appropriate based on their expertise, and roles as they have been outlined in the executive committee description proposal.

Selection Process

Current selection process of the executive committee will be done by slates of candidacy from the coalition as a whole in addition to self-nomination.

Executive Committee Description

The full coalition must vote to elect one executive committee chair and two vice chairs, when possible, to share leadership responsibility over the coalition. Each will be elected to serve for a one-year term, which may run consecutive unless otherwise deemed by the entire coalition. In order to facilitate a successful transition of leadership to newly elected executive committee members, a one-year term may extend past one year as needed. The coalition will nominate and elect successor committee members from its membership within two months of the outgoing members expired term or upon resignation. By January the member's whose term is expiring must make a call for nominations to be submitted.

Whenever possible, at least one of the three committee members will be a gender variant or transgender person. An unexpected vacancy in the office of chair will be filled for the duration of the unexpired term by a special election of the full coalition. The full coalition may remove committee members by a simple majority vote as deemed necessary.

The executive chair's duties and responsibilities include, but are not limited to:

- Serve as official coalition spokesperson, representing the coalition to the general public and other interested parties as necessary.
- Facilitate coalition meetings to ensure issues are adequately discussed and resolved as appropriate.
- Facilitate coalition executive committee meetings.
- Organize, motivate, and empower coalition members in support of all coalition projects, business, and events.
- Notify/Remind coalition members of member's responsibilities as needed.
- In consultation with the vice chairs, delegate such responsibilities and duties as appropriate to the executive committee.
- Assisting and supporting vice chairs as needed.
- Orient new coalition members as needed.
- Assist in facilitating successful changeover of newly elected executive chair.

The vice chair's duties and responsibilities include, but are not limited to:

- Assist in representing the coalition to the general public and other interested parties as necessary.
- Work with executive chair in coordinating coalition business and meetings.
- Assisting and supporting the executive chair as needed.
- Coordinate and take the lead in recruitment of new coalition members.

- Create and coordinate member work groups as needed.
- Organize, motivate, and empower coalition members in support of all coalition projects, business, and events
- Assist the executive chair in setting and preparing coalition meeting agendas.
- Work with executive chair and in coordinating coalition business and meetings.
- In case of absence of executive chair, facilitate coalition executive meetings.
- In case of absence of executive chair, facilitate coalition meetings to ensure issues are adequately discussed and resolved as appropriate.
- Assist in facilitating successful changeover of newly elected vice chairs.

Rules of engagement (e.g. Roberts' Rules/consensus)

Coalition members will respect each other's time.

The board will maintain a commitment to respect the diversity of the transgender/gender variant communities.

Bylaws interpretation

Interpretation of the bylaws shall be made by the executive committee and by a majority vote, should the coalition disagree about an article of the bylaws.

Membership Responsibilities

To provide input throughout the coalition development process and share in decision-making, prioritizing prevention needs, reporting trends in community attitudes and behaviors, highlight local efforts, review materials, and disseminate information about the coalition to local communities.

Expectations

Members have four primary expectations; communication, attendance, active & engaged participation and time commitment. Coalition work will add up to roughly 2-3 hours/week of your time.

Working Groups

Working groups will form with a specific goals or tasks to complete and an end date assigned. They will be comprised of coalition members, executive committee members, and potential collaborators from within the community.

Preparation

Members are expected to read all relevant materials prior to the meetings.

Commitments

Members should follow through in commitments made to the coalition.

Terms (duration of coalition service)

There is a minimum two year commitment. There is no limit to the number of terms a member may serve.

Removal

Membership may be terminated for any of the following reasons; failure to meet the meeting attendance requirements; conduct in conflict with the purpose of the coalition; behavior divergent from the mission of the coalition. Removal of a board member is first recommended by the coalition, and then decided on by the executive committee through a majority vote.

Quorum

51% of the total coalition will constitute a quorum.

Decision-Making

Decision making shall be done by voting. Votes are passed with 51% support.

Bylaw Changes Bylaw changes can be proposed by any voting coalition member in good standing. Changes to these bylaws shall be by consensus. If no consensus can be reached after a thorough discussion, then 51% majority rules shall be used.

ATTACHMENT E: EXAMPLE RESOURCE INVENTORY METHODOLOGY & QUESTIONNAIRE

Local coalitions are made up of consumers, stakeholders, and providers of services. The vast knowledge of coalition members will be a good place to start building a list of resources. The **Questionnaire Template** below provides guidance that you can base your resource inventory on.

Name of Transgender Specific Program	
Name of Host Organization	
Program Street Address	
City	
State	
Zip Code	
Phone Number	
E-Mail Address	
Website URL	
Primary Contact Person and Title	
Primary Populations Served	
Bi/Multilingual Services	
Specific Services Available	

ATTACHMENT F: DATA COLLECTION RECOMMENDATIONS

For a more detailed version please visit our website at www.transhealth.ucsf.edu.

Counting Trans Populations

It's Important to Be Counted!

Many local, state, and federal agencies do not accurately count trans people. Data collection forms often do not provide ways for transgender, genderqueer, or other gender variant people to indicate their gender identity. Many forms that try to be inclusive of trans identities often only list three categories: male, female, or transgender. This method of data collection lumps all trans people together into one category, which does not allow us to distinguish transwomen from transmen or genderqueer people and makes the data difficult to interpret or apply to a target population.

Some trans people may not identify as transgender, may live stealth, and/or may be afraid to tell people about their gender history--so even if given the opportunity to indicate this on a data collection form, they still may not choose to do so. Often transwomen are lumped into the "men who have sex with men" (MSM) category, which does a disservice to transwomen and results in inaccurate data collection. Not only is categorizing transwomen as MSM disrespectful of their gender identity, it means that even though transwomen are counted in data that are used to fund HIV programs, transwomen often do not benefit from the programs that are developed on the basis of that data. Transwomen have different needs, lifestyles, and concerns than MSM, and programs need to be developed with their uniqueness in mind. The CDC is currently looking at ways to revise its data collection and classification methods to make them more accurate and inclusive of trans people.

How Many Trans People Are There?

Worldwide estimates for transwomen are 1 in every 30,000 people. Transmen are estimated at 1 in every 100,000 people. (1, 2) However, these numbers are likely an underestimate because they only account for trans people diagnosed with Gender Identity Disorder and/or people receiving services at gender clinics, which we know are not inclusive of all trans people.

How to Accurately Capture Data on Trans Clients

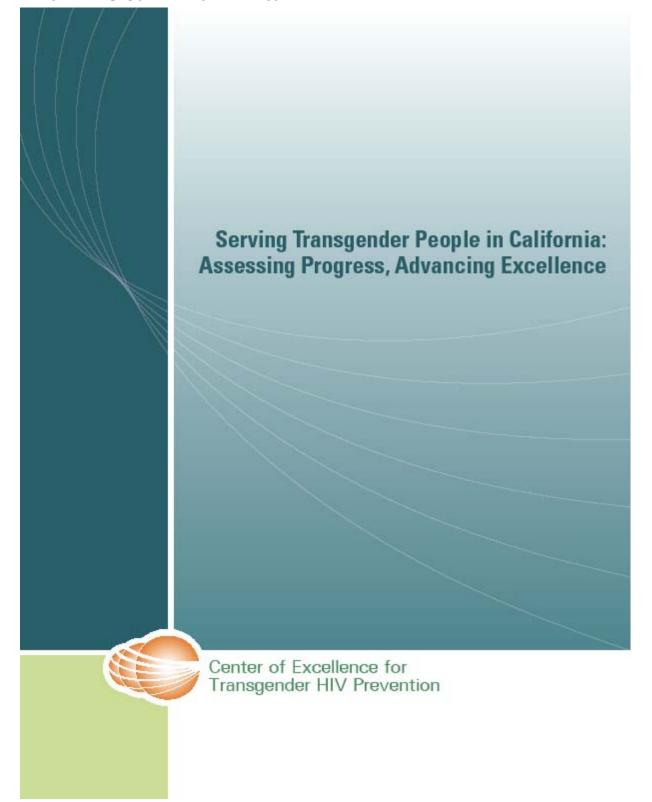
We strongly encourage the use of a two-question method to accurately collect data. Change ALL intake forms in the agency to contain at least the following two questions: (3)

1.	What is your gender? (Check all that apply)
	□ Male
	☐ Female
	☐ TransMale/Transman
	☐ TransFemale/Transwoman
	□ Genderqueer

	☐ Additional Category (Please Specify):
	☐ Decline to State
2.	What sex were you assigned at birth?
	□ Male
	□ Female
	□ Decline to State

This may be more information than your funders require. But we want to encourage you to collect such information since it is better to collect more information in order to capture the data correctly, communicate inclusivity to your clients, and accurately reflect the clients you are serving. This extra information can be condensed later for reporting purposes.

ATTACHMENT G: SUMMARY OF FINDINGS



The Center of Excellence for Transgender HIV Prevention (CoE) is a

collaboration between the Pacific AIDS Education and Training Center (PAETC), and the Center for AIDS Prevention Studies (CAPS) at the University of California, San Francisco, funded by the California Department of Public Health, Office of AIDS.







The CoE's mission is to provide leadership, capacity building, professional training, policy advocacy, research development, and resources to increase access to culturally competent HIV prevention services for transgender people in California.

Table of Contents

<u>Acknowledgements</u>	33
Introduction and Background	34
HIV rates among transgender people	34
Purpose of the Resource Inventory	35
Methods	36
Results	37
Agency characteristics	37
Barriers and facilitators to implementation of transgender-specific program	38
Barriers and facilitators to recruitment and retention of clients	40
Funding Recommendations	45
Best Practices for Transgender HIV Prevention.	49
<u>References</u>	53
<u>Appendices</u>	56
Summary table of Transgender HIV Prevention Programs in California	56
Resource Inventory Program Questionnaire	57

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California Department of Public Health, Office of AIDS

(<u>Disclaimer</u>: All analyses, interpretations, and conclusions are exclusively attributable to the CoE, not to the State Office of AIDS.)

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Introduction and Background

Transgender people are highly vulnerable and marginalized in the United States. Experiences of discrimination are common when seeking to obtain basic human necessities such as employment, housing, and health care, as are reports of violence and harassment (1-8). It comes as no surprise then, given the association of negative health outcomes with stigma and discrimination, that transgender people, and transgender women and transgender people of color in particular, experience severe health disparities across a number of outcomes, including HIV (5, 9, 10).

HIV rates among transgender people

Currently there are no national estimates of the prevalence of HIV among transgender populations due to lack of data collection on transgender populations at the national level. Currently, transgender women (and sometimes transgender men) are miscategorized as men who have sex with men (MSM), and there are no population-based studies that provide us with an estimate of the size of the transgender population in the US. However, regional reports of HIV rates have been found to be consistently high among transgender women, especially among Latinas and African-Americans. Rates of HIV among transgender women have been reported in the ranges of 14% to 68%, depending on which subgroup was sampled (11, 12) with 35% in San Francisco (2), 32% in Washington DC (13), 27% in Houston (14), and 22% among MTF ethnic minority youth in Chicago (3). A recent meta-analysis of 29 studies conducted in cities across the United States found that 28% of transgender women tested positive for HIV when results were lab-confirmed, and 12% of transgender women were HIV positive by self-report, a finding that suggests an increased need for testing (15).

In California, transgender female clients of publicly-funded counseling and testing sites have higher rates of HIV diagnosis (6%) than all other risk categories, including MSM (4%) and partners of people living with HIV (5%), and African American transgender women have a substantially higher rate of HIV diagnosis (29%) than all other racial or ethnic groups of transwomen (16). Estimates from California's urban centers also suggest that HIV prevalence rates among transgender women are extremely high, especially for transgender women of color and African American transgender women in particular (2, 15). Regional estimates include 16 - 60% in San Francisco (2, 17-20) and 22 - 52% in Los Angeles (21, 22) with the highest rates consistently being reported among African American transgender women. A needs assessment in San Diego reported 15% of their participants were HIV-positive (23). However, this is possibly an underestimate of the true rates of HIV among transgender women in San Diego because almost a quarter (22%) of their participants did not respond to the HIV status question, only 80% of those who did respond reported ever being tested for HIV, and they had difficulty recruiting sex workers for participation (23).

The California HIV/AIDS Monthly Summary Report as of May 31, 2008 reports that 277 transgender people are currently living with HIV and 556 and living with AIDS. The total number of transgender people living with HIV/AIDS in California is estimated at 833, according to this report. This data does not differentiate between transgender women and transgender men, and is likely to be an underestimate, due to the difficulty in estimating the number of transgender people living in California, the reluctance of transgender people to come out as transgender in testing situations, and the reluctance of transgender people to access testing. It is likely that many transgender people are categorized as 'male' or 'female' in testing situations because the test counselor either fails to ask about their gender, clients report their gender as 'male' or 'female' to reflect their current gender identity, or clients do not disclose their transgender status due to fear of mistreatment by the

provider. Many transgender people who may be living with HIV avoid testing altogether due to fear of a positive diagnosis and/or distrust of service providers due to past negative experiences. A national meta-analysis found that when HIV status was confirmed with lab testing, 28% of transgender women were positive for HIV, whereas only 11% were positive when HIV status was measured by self-report, calling attention to the need for increased testing among transgender women at risk (15).

Very little research has been conducted on the distinct HIV/STD risks and prevention needs of transgender men, despite anecdotal evidence that some transgender men could be at high risk. Transgender men, like other people, claim a variety of sexual orientations and have sex with various types of sexual partners (24). Early research studies that reported HIV prevalence rates among transgender men either did not specify the gender of their sample's sexual partners or have predominately included men that identify as heterosexual (transgender men that primarily have sex with women) (2, 25). The few studies that report HIV rates among samples of transmen have reported 2 – 3% prevalence (2, 13, 24). Due to such low reported rates of HIV, there has not been much emphasis on further exploration of HIV risk behaviors among transgender men.

However, some evidence suggests that there is a significant subgroup of transgender men that engage in high-risk sex with non-transgender men and some transgender men who engage in sex work (26). Initial data suggest that many transgender men have sex with non-transgender men and that misconceptions exist about their level of risk of exposure to HIV (20). Because the current California HIV/AIDS Monthly Summary reports do not distinguish between transgender women and transgender men, it is unclear how many transgender men in California are currently living with HIV. Because so little research exists on HIV risk and prevention needs of transgender men and those with gender identities that do not adhere to a binary classification system, much of what we currently know about HIV rates and prevention among transgender people focuses on transgender women.

Purpose of the Resource Inventory

The Center of Excellence for Transgender HIV Prevention (CoE) was created in July 2007 with funding from the California Department of Public Health, Office of AIDS, to provide leadership, capacity building, professional training, policy advocacy, research development, and resources to increase access to culturally competent HIV prevention services for transgender people in California. It is a collaborative partnership that combines the unique strengths and resources of a renowned training and capacity building institution, the Pacific AIDS Education and Training Center (PAETC), and an internationally recognized leader in HIV prevention research, the Center for AIDS Prevention Studies (CAPS), both of whom are part of the University of California, San Francisco (UCSF).

Early in its development, the CoE identified the need to synthesize information about existing programs that address HIV prevention needs among transgender people in California in order to identify service needs that are currently being met as well as those that remain unmet. To achieve this goal, we have compiled a Resource Inventory and Service Gap Analysis of transgender HIV prevention programs in California. This report is based on a review of existing literature examining current issues in HIV prevention among transgender people and our analysis of data we have collected describing the services that are currently being provided in California. In this document, we describe common barriers and facilitators to successful program implementation and management, outline services that are still needed, identify which subgroups of transgender people are not adequately being served, generate recommendations to inform the allocation of resources, and summarize Best Practices for Transgender HIV Prevention.

Methods

Based on our existing knowledge of transgender-specific HIV prevention programs in California, the CoE staff compiled an initial list of programs to consider for inclusion in the Resource Inventory. We presented this list to the CoE Community Advisory Board (CoE CAB), who reviewed the list and offered information about additional programs to include and contact information for those programs. We then spent several months systematically contacting programs to ensure that the programs were indeed transgender-specific HIV prevention programs and to invite their participation in this Resource Inventory. We also conducted traditional literature and internet searches to identify additional programs, and asked program staff of participating programs to refer us to additional programs that were not yet included. For inclusion, HIV prevention programs were required to be transgender-specific and/or market their HIV prevention services specifically to transgender people. Thus, general transgender support groups, substance abuse treatment programs, social groups, etc. as well as broader HIV prevention programs that may or may not reach transgender people were not included. Future versions of this Resource Inventory may include this broader scope of services to transgender people in California.

To collect data on the programs identified for inclusion, we designed a qualitative questionnaire to gather basic contact and staffing information as well as more detailed programmatic information, such as host organization and transgender program funding, mission statements, specific services provided, priority populations, history of transgender program, number of clients reached, barriers and facilitators to implementation, recruitment and retention issues, and best practices. The full questionnaire is included in Appendix A. The Data Collection Working Group of the CoE CAB was formed to review and pilot the initial draft of the questionnaire. Following the pilot, the format of the questionnaire was revised based on Working Group feedback so that staff from the programs could enter the information directly into the electronic document and return it by e-mail instead of requiring a phone interview for completion. The Working Group determined that this would add to the ease and efficiency of the data collection process since program staff have much of the required information in electronic form, some of which is difficult to recall during an interview. At the end of the questionnaire, we asked program staff to refer us to any additional transgender-specific HIV prevention programs in their area in order to ensure comprehensive coverage.

All information included in this report is based primarily on data collected from program staff of participating agencies providing HIV prevention services to transgender people in California. The agencies varied widely in degree of depth and specificity of their responses to the questionnaire items and not all agencies that were identified for inclusion in this Resource Inventory returned the questionnaire. Basic information about the programs that did not return completed questionnaires was obtained through program websites; however, more detailed information in this report is based only on those programs that participated in the data collection process. Thus, the information presented in this report is limited by the level of participation, accuracy, and detail offered by the agencies themselves. When necessary, the information provided was supplemented by information available on the program's website, or by following up with program staff via telephone or email with questions. An initial draft of this report was reviewed by the CoE CAB to incorporate their suggestions and expertise.

Results

Agency characteristics

Questionnaires were distributed to 22 agencies that represent 24 programs that serve transgender clients. (Some agencies provided information on more than one transgender-specific HIV prevention program.) Of the 22 agencies, 16 agencies returned the questionnaire representing 18 distinct transgender-specific HIV prevention programs, yielding a 73% response rate. Five programs are located in Los Angeles County, 10 are in San Francisco County, one is in Santa Clara County, one in San Diego County, and one is located in Alameda County.

Table 1 summarizes the transgender-specific HIV programs we identified in California by location, priority populations, and primary services available. All programs specifically prioritize transgender women, and 7 explicitly expressed that they are inclusive of transgender men. (Some programs may provide additional services or include transgender men but did not explicitly indicate so. The data in the summary table is limited by what was reported by the agencies themselves and/or the data available via their website.)

All of the host organizations of participating programs reported that they had conducted or received transgender-specific trainings for staff. Funding and staff varied considerably among agencies. Yearly budgets for trans-specific programming ranged from 0 - 383,000, with some programs reporting that rather than have funding specifically allocated for separate trans programming, transrelated services are integrated into their larger organization. The average number of staff for transspecific programs was 3 (range: 1 - 8), although most agencies did not report the full-time equivalency (FTE) of their staff, so the actual number of average staff hours per week is likely to be less than 3 FTE. The average number of years since implementation of the trans-specific program was 7.3 years (range: 1 - 14), although many of the older programs reported significantly strengthening or expanding their trans-related programming within the past 2 to 5 years.

Some of these programs are specifically set up to facilitate increased access to mainstream medical services for transgender clients and/or increase the availability of culturally competent care. These programs varied in how they were structured to accomplish this goal. For example, Lyon Martin Health Services and Dimensions Clinic in San Francisco do not have a trans-specific program, but instead integrate transgender care into all of the services provided. Other programs, such as Project STAR (Supporting Transgender Access to Resources) of Family Health Centers in San Diego, TransVision of Tri-City Health Center in Fremont, and the Risk Reduction Program of Children's Hospital, Los Angeles, are housed within larger medical centers that provide comprehensive primary care services that are available to transgender clients.

Other programs, such as the Transgender HIV/AIDS Program of the Instituto Familiar de la Raza and the Asian & Pacific Islander Transgender Empowerment (ATE) Program of API Wellness Center, both in San Francisco, are ethnic-specific transgender programs housed within larger social service agencies that serve a specific ethnic group.

Table 2. Programs by type of host agency

Medical clinics serving trans clients (no trans-specific program)

Lyon Martin Health Services (San Francisco) Dimensions Health Clinic (San Francisco) St. James Infirmary (San Francisco)

Trans-specific programs housed within large medical clinics

TransVision (Tri-City Health Center, Fremont)
Project STAR (Family Health Centers of San Diego)
Risk Reduction Program (Children's Hospital, Los Angeles)
Transgender Harm Reduction Program (Children's Hospital, Los Angeles)
Transgender Tuesdays (Tom Waddell Health Clinic, San Francisco)

Trans-specific programs housed within an ethnic-specific social service agency

TRANS:THRIVE (Asian & Pacific Islander Wellness Center, San Francisco)
API Transgender Empowerment (Asian & Pacific Islander Wellness Center, San Francisco)
Serving Transgenders At Risk (Asian Pacific AIDS Intervention Team)
Instituto Familiar de la Raza (San Francisco)
Bienestar (Southern California, multiple locations)
Transcending (Ark of Refuge, San Francisco)

Trans-specific programs hosted by larger coalitions/organizations

El/La Programa para Trans-Latinas (Mobilization Against AIDS, San Francisco) TransAction and A.S.K. (Friends Research Institute, Los Angeles) TransPowerment (Community Health Partnership, Santa Clara) Transgender health education group (Forensic AIDS Project, San Francisco)

Barriers and facilitators to implementation of transgender-specific program

1. Adequate funding is crucial to successful program implementation.

By far, both the greatest barrier and strongest facilitator to successful program implementation cited by participating programs was funding. Applying for funding is difficult for agencies that do not have adequate information about their priority population due to data collection issues that result in underestimation of the size of the transgender community and limited research about the needs of transgender people in their local area. Securing the initial funding for implementation of a transspecific program was especially difficult for those whose host organization administrators and/or funders lacked a sense of urgency about the need for such programming. When the trans-specific program had buy-in from the larger organization, however, that support was cited as a tremendous facilitator to implementation.

When funding is scarce, the ability of trans-specific programs to meet the needs of their clients and provide adequate services is severely limited. Budget cuts are disheartening and deeply felt by

programs already operating on a very tight budget, and the de-funding of other local services makes it difficult for existing programs to provide successful linkages to services that are not available at their agency. However, when the host organization of the transgender-specific program has strong funding streams and is able to provide much-needed institutional infrastructure and support, it seems that programs are able to thrive even when their transgender-specific programming budget is relatively modest. Program staff repeatedly cited the need to pursue funding aggressively and continuously to sustain, and preferably expand, their services.

2. Recruitment and retention of appropriate staff is critical, but can be difficult.

Limited funding also serves as a barrier to adequate staffing. Programs reported difficulty finding and retaining staff with the appropriate training and skills for the positions they sought to fill, in part because they are not able to provide adequate compensation. In addition, because funding for salary support is limited, programs are not able to hire enough staff to handle the demands of the work, leading to burnout and high staff turnover. Programs that are able to tie their funding to research and training grants reported less turnover due to their ability to offer more competitive compensation, benefits, and stability for their staff.

It is extremely important that the staff of trans-specific HIV prevention programs reflect the diversity of the clients they serve. However, this also means that transgender staff often struggle with the same types of issues as the clients they serve, such as having had limited educational opportunities, job training, and formal work experience. Additional training, mentoring, and support are often required to support appropriate staff that are also skilled in service provision. Managers and supervisors need to be supportive, flexible, able to provide constructive feedback, and committed to ongoing staff development. Often the managers and supervisors themselves are overworked and underpaid, leaving insufficient time and resources for them to devote to proper management and leadership.

Initial training is very important, although what really matters is the support that the staff gets on a day-to-day basis. Ongoing supervision is vital to the success of the staff and the program. Programs need to budget money for training and also account for the extra time it takes to supervise staff who may need a lot of ongoing support to perform their job duties.

— TRANS:THRIVE

San Francisco, CA

3. Community involvement in program development can facilitate successful implementation.

Few programs have the resources to conduct thorough needs assessments in their communities, either prior to applying for funding or during the program development phase. Agencies reported that creating a Community Advisory Board facilitated the process of program development and implementation, especially when other types of information about the communities they aim to serve is scarce. Other agencies held focus groups with community participants and gatekeepers to assess needs and inform programmatic decision-making. In general, community support and involvement was cited as a major facilitator to successful program development and implementation.

Many programs reported that as they were developing their trans-specific program, they found that the needs of the community were so high that they felt they were not always able to meet the expectations of the clients they were serving. While the demand was certainly there for the services they hoped to provide, they also felt that clients, as well as staff, were often frustrated by the inability of the programs to meet the wide variety of their clients' even basic needs (employment, housing,

school, safety, etc) due to the increased difficulties of violence, discrimination, and transphobia that transgender people face.

Barriers and facilitators to recruitment and retention of clients

1. Many transgender people are transient, presenting a challenge to client recruitment and retention.

Some subgroups of transgender communities are particularly transient, such as recent immigrants, youth, those who are homeless, and those with unstable or no employment. Reaching transient people can be especially difficult as eligibility requirements for accessing services increase, such as proof of residency in the city or county where services are offered. Providing proof of residency is difficult for youth who may not be living with their families due to rejection and/or violence, those who do not have access to affordable housing and are living on the streets, with friends, or in hotels, and recent immigrants who may not have established US citizenship. In addition, transgender people who have recently immigrated may avoid seeking services due to fear of discovery of undocumented immigration status. Furthermore, many agencies do not have the resources to offer multilingual services and materials for monolingual, non-English speaking clients.

Incarceration can also lead to difficulties in client retention. Because transgender people are incarcerated at disproportionate rates compared to the general population, services for many clients are disrupted by incarceration and agencies may lose track of clients who are in and out of custody. Substance abuse often leads to incarceration, and if clients are not released directly into a substance abuse treatment program, they frequently relapse and the cycle of incarceration continues.

2. Transgender communities are diverse, and trying to meet all of their varying needs can be extremely difficult.

For agencies in areas where they are one of the only (or perhaps the only) organization serving transgender people, serving diverse clients at the same agency can prove to be difficult, if not impossible. In any community, different groups of transgender people have widely varying needs, identities, and experiences, and attempting to accommodate this variety can be quite taxing on agencies who are trying their best to meet different clients' expectations. Most agencies reported that they primarily serve a particular ethnic group. Even when they did not specifically prioritize a particular ethnic group, some agencies found that once their organizations gained a reputation for serving a certain segment of the population, other groups were less likely to seek services there. The agencies that reported attracting many different ethnic groups, as well as youth and transgender men, were more likely to be larger programs that offer a wide range of medical services, often including primary care and hormone provision, in addition to their HIV prevention services.

3. Past experiences of stigma and discrimination discourage clients from seeking services.

The severe stigma and discrimination that transgender women experience underlie many of the risk behaviors frequently reported in this population (27, 28). The effects of stigma and discrimination, including low self-esteem, economic instability, isolation, distrust of service providers due to past negative experiences, and reluctance to seek services until in crisis mode, can create barriers to providing effective services to transgender clients, including HIV testing. Many agencies noted that it takes time to gain the trust of the transgender community due to clients' past negative experiences with service organizations, and that if a transgender client has a negative experience or does not get what they are looking for from an agency, they are often unlikely to return in the future.

The personal and social effects of discrimination, low self-esteem and barriers to economic stability are just a few of the issues that cause isolation and make it difficult to reach some clients and provide much needed services.

 Transcending Youth Prevention Program, Ark of Refuge San Francisco, CA In addition to the stigma associated with being transgender, the stigma and denial around HIV risk and the fear of receiving a positive HIV diagnosis leads many transgender people to avoid testing. HIV status is often not discussed among transgender women or their sex partners (20), so HIV prevention programs have the difficult task of creating new norms around discussions of risk and disclosure. In addition, many transgender people are faced with pressing issues of daily survival, such as housing, unemployment, and substance abuse, so HIV prevention or treatment is not seen as a high priority.

4. Hiring transgender staff at all programmatic levels is essential for a transgender HIV prevention program to be successful.

The most frequently cited facilitator to recruiting and retaining clients and addressing the aforementioned challenges is hiring transgender staff, especially those who are well-networked in the community and those who can serve as role models. Transgender clients often feel most comfortable with outreach and program staff who are also transgender, and transgender staff who already have established relationships with the community that the program seeks to serve can be indispensable in terms of recruitment and retention. In addition, transgender staff who have personal experience with many of the same issues that clients face can offer unparalleled support, guidance, and mentorship. Transgender staff who are openly living with HIV can model disclosure about status to help reduce stigma in the community. In addition to hiring transgender outreach workers and front line staff, successful programs involve transgender people at every level and stage of program development to ensure community relevance and engagement. Hiring qualified transgender people as managers, directors, and researchers also sends a strong message to all staff and consumers about your organization's commitment to diversity and supporting highly marginalized communities.

Service Gap Analysis for Transgender HIV Prevention in California

The Center of Excellence for Transgender HIV Prevention identified the following service gaps by comparing what we know about the HIV prevention needs of diverse groups of transgender people with the data we collected about services currently being provided in California.

One limitation to note is that service gaps in rural areas are not adequately described by our data, since programs that participated in the Resource Inventory all represented urban regions of California. However, because we were not able to identify any transgender HIV prevention programs in rural locations, we can be fairly certain that there are transgender people living in these areas experiencing isolation and difficulty accessing services.

I. HIV prevention programs are currently concentrated in San Francisco and Los Angeles; there is a need for programs that serve other parts of California.

While funding should continue to reflect the epidemic, which is concentrated in urban epicenters, currently there are not adequate services for transgender people that do not live in major metropolitan areas. For the singular programs serving Alameda, San Diego, and Santa Clara counties, there are inherent difficulties in attempting to meet the needs of large, diverse groups in their region. Additionally, in some areas, transportation is an issue for transgender clients seeking services. Transgender people may be spread out across the area or agencies may not be located where transgender people live and work. This sets up a barrier to accessing care for many transgender people who do not have access to cars or money for taxi fare. Currently, many transgender people must travel great distances to access competent primary care services, such as those offered by the Tom Waddell clinic in San Francisco.

2. <u>Transgender people who are undocumented or recent immigrants are not adequately being reached by current HIV prevention efforts.</u>

A lot of transgender Latinas do not stay in one place for too long.

EI/La Programa para Translatinas
 San Francisco, CA

Transgender people often migrate to the US seeking refuge from transphobia in their home countries. These recent immigrants are often monolingual, non-English speakers who are fearful of accessing services due to fear of revealing their immigration status. Agencies reported that requiring clients to "show the right papers" acts as a barrier to providing much-needed services. In addition, agencies are under-equipped to provide multilingual services and materials.

3. <u>Service disruption is common when transgender people become incarcerated</u>. There was only one program in California (Forensic AIDS Project of San Francisco) that was identified as specifically serving incarcerated transgender people. Given the disproportionate rates of incarceration, especially among transgender women of color and sex workers (2), and the fact that incarcerated women report unprotected sex while incarcerated (21), there is a strong need for HIV prevention services during incarceration that is not currently being met.

4. <u>Current programs are often difficult to access for transgender women engaged in sex work.</u>

Many transgender women (and some transgender men) engage in sex work to simply survive or to supplement their income to fund gender confirming procedures (28). Due to transphobia in education and employment, many transgender people do not have the education or job skills to transition out of sex work (27). Sex work is a demanding lifestyle, requiring people to sleep most of the day in order to do sex work at night, making it is difficult to keep daytime appointments at service agencies. Transgender people who engage in sex work are exposed to physical violence, sexual assault, and police harassment. Sex work may also intensify drug use and

Don't give up. Working with incarcerated populations is challenging since the laws that govern serving incarcerated populations bind us. However, ensuring that people in the community do not forget about those who are incarcerated helps to chip away at the stigma that incarcerated populations face when they return to their communities.

Forensic AIDS Project
 San Francisco, CA

vice versa, when people engaged in sex work use substances to cope with the stress inherent in the work, and then sex work becomes the means for obtaining the substances.

5. Transgender youth are often left out of HIV prevention education.

Much of the HIV prevention education available to youth happens within schools, but because transgender youth often drop out due to stigma, harassment, and violence (3, 29), they do not receive this critical information. Many existing programs that purport to serve LGBT youth do not have the capacity to properly address the needs of transgender youth. Transgender youth need access to substance abuse treatment, housing, hormone therapy, GED programs, employment and legal services, and comprehensive sexuality education that includes youth tailored health and HIV prevention messages, services, and programming to increase knowledge, build effective skills, and create opportunities for health promotion and sustaining health lives. Because many transgender youth are simply struggling to survive, HIV is often not their highest priority; for example, recent studies have reported that 26% - 47% of trans youth have attempted suicide (5). Creating services and programs that are comprehensive and reflective of trans youth specific health and wellness needs may be preferable to simple HIV prevention.

6. Services and programs for non-transgender partners of transgender people are needed.

Transgender women report diversity in terms of sexual orientation and partner with people of all genders. Very rarely do the partners of transgender people have access to support and HIV prevention information that is specifically relevant to them. It is important that transgender people are able to include their partners in their HIV prevention strategies and support networks. While it is important to support all partners of all genders, the greatest current risk factor for transgender people is their male sexual partners. Transgender people with male partners living in urban areas where HIV rates are high are at greater risk of exposure to HIV because there is a higher chance that male partners will be living with HIV (30).

7. Transgender men, especially those who have sex with non-transgender men, have unmet HIV prevention needs.

Programs that provide HIV prevention services to MSM clients need to be educated about the needs of transgender men and their non-transgender male partners. HIV/STD rates among transgender men appear to be about 2%, although very little information is available (25, 26, 31). Although HIV among transgender men appears to be low compared to transgender women, studies of risk behaviors among transgender MSM indicate that more information is needed. If HIV/STD rates are indeed low among transgender MSM, we need to know more about what prevention strategies transgender MSM are currently using and design interventions to support protective factors and keep it low. Intervention strategies may need to specifically target issues around self-esteem, body image, gender identity, communication skills, and HIV prevention education that includes partners of transgender men.

8. It can be difficult for agencies to define their priority population, sometimes resulting in omission of certain segments of the population they intend to reach.

API transgenders are a selective community that are fewer in numbers and assimilate into mainstream society, making them more difficult to locate. The more involved and connected a certain staff person may be in the API transgender communities, the more likely these challenges become negligible.

STAR (Serving Transgenders At Risk),
 APAIT
 Los Angeles, CA

Many agencies noted that some segments of the community are more difficult to locate for outreach and service provision, and if they are accessing services, are often not accurately counted in data collection methods. Some clients may identify as 'post-transsexual', or as a 'woman (or man) of transsexual experience', which describes the fact that their current identity is 'female' or 'male', but acknowledges their history of transition. These clients may live 'stealth', meaning that they do not openly identify as transgender.

In addition, people who identify as "genderqueer", "third gender", and/or people

who do drag or present as female as part of the ball scene may or may not identify as transgender, and agencies often express confusion about whether or not to include them in their priority population.

9. Native transgender people are currently underserved.

When population size is taken into account, Native Americans (including American Indians and Native Alaskans) are ranked third in rates of HIV/AIDS diagnosis, according to the CDC's 2005 HIV Surveillance Report. However, current programs for transgender people are not adequately reaching Native Americans. Native Americans are more likely to live in rural parts of California, which may translate into decreased access to services for transgender Native Americans. In addition, due to the diversity of tribal beliefs and cultures, it may be difficult to design culturally specific programs that adequately address the needs of transgender Native Americans.

Funding Recommendations

1. <u>Transgender-specific</u>, comprehensive health care at one accessible site increases access to care for transgender people.

Transgender people are in dire need of access to comprehensive, culturally sensitive, and affordable health care. Transgender-specific clinics that offer a range of diverse services are needed, in addition to the integration of transgender competent care in mainstream health service organizations. Many transgender people purchase hormones on the street without a prescription, and their use can be unsafe when not monitored by a medical professional. The provision of hormone therapy is neither costly nor difficult, and transgender people's quality of life is markedly improved through appropriate hormone use.

Benefits of setting up comprehensive heath care sites for transgender people include:

- ✓ Hormone provision and supervision provides incentive to address other heath care needs, such as mental health care, substance abuse treatment, HIV care and treatment
- ✓ Providing the means to address these other health care needs at the same site eliminates barriers to care and provides direct linkages to additional services
- ✓ Providing both HIV prevention and care services at one site eliminates the barrier of fear of loss of confidentiality for transgender people living with HIV
- ✓ Allows providers to focus on overall well-being rather than HIV prevention exclusively
- ✓ Support can be provided for those who seek out a physical transition process, including education about transition-related medical procedures and the dangers associated with silicone injections,
- ✓ Non-traditional strategies for care provision can be adopted, such as flexible appointment hours, private appointments, and evening and weekend hours.

2. Provision of hormone therapy can increase access to HIV care and treatment.

It is neither costly nor difficult to provide competent care to transgender individuals, and with careful monitoring there are very little negative side effects. In fact, according to many clinicians, quality of life for transgender people is improved through appropriate hormonal therapy.

Tom Waddell Health Center
 San Francisco, CA

Receiving hormones is often an incentive for addressing HIV among transgender women, and hormone provision provides a mechanism for health promotion and prevention of other diseases (32, 33). Primary care providers for transgender people need to enhance their HIV expertise, and vice versa. Every visit should be an opportunity to assess for risks and review prevention strategies with the patient. Transgender people who know they are living with HIV often do not have a regular medical provider or do not see their provider on a regular basis, due to concerns about confidentiality, lack of transgender sensitivity in

services, and past negative experiences with HIV treatment providers. Transgender women express concerns about receiving HIV care somewhere where other transgender women will be, because they fear it will result in the loss of confidentiality. These concerns can be alleviated by providing HIV care in the context of hormone therapy. In addition, HIV positive transgender people need to be educated on the importance of adherence (34).

3. HIV testing among transgender people and their partners needs to be increased.

People who know they are HIV positive are more likely to seek medical care and change their behavior. More timely diagnosis of HIV can improve treatment and care, prolong survival, and reduce the spread of HIV. HIV is most often transmitted by people who are unaware of their status (35). Programs need to be reaching those who do not yet know they are HIV positive, connecting those who test positive to care, ensuring continued access to care, and re-emphasizing prevention among those who test positive. Testing is an educational opportunity for everyone, regardless of HIV status. HIV testing needs to be normalized among transgender people and their partners, and barriers to testing must be addressed. HIV status is not shared among transgender women who are engaged in sex work because accusation of HIV positive status can be used as a weapon against other sex workers to secure "dates". Loss of confidentiality is a major fear among transgender female sex workers, due to the threat of loss of income and means of survival (36). Testing sites need to take this into consideration when planning their services for transgender women.

4. There is a need for development of evidence-based HIV prevention interventions that are transgender-specific.

Despite high prevalence rates, public health intervention research has produced no culturally specific, evidence-based HIV prevention interventions for transgender women. Of the few published interventions that have been implemented with transgender women, none have been controlled trials or were rigorously evaluated for effectiveness (37-39).

Given the complex sexual risk factors present among transgender women, HIV prevention programs developed for other populations that are simply adapted to include new language will not ultimately address the cultural context in which risk behaviors occur and in which protective factors develop (40). HIV prevention interventions need to be based on the culture and context that most influence the lives of transgender women. Some unique risk factors may include hormone use, silicone injections, limited employment opportunities, and transphobia. Three programs included in this Resource Inventory were adapted from Evidence Based Interventions (EBIs): Risk Reduction Program at Children's Hospital in LA: Popular Opinion Leader and Adult Identity Mentoring and Bienestar's SISTA: Sisters Informing Sisters about Topics on AIDS.

There are a lack of resources for conducting needs assessments (especially with youth and transmen), evaluating existing programs, and providing competent and on-going technical assistance or consultations for organizations providing services to transgender individuals. Future needs assessments might examine non-HIV-specific activities and resources that may contribute to reducing risk behavior. These needs assessments could then be utilized to inform culturally-specific interventions for transgender people.

5. Service gaps need to be addressed.

Service gaps may occur because no services are currently available or because available services are either not appropriate for or not accessible to the priority population. Currently, there are a number of subgroups of transgender communities that are being underserved, including youth, incarcerated transgender people, monolingual non-English speakers (including recent immigrants), Native transgender people, and partners of transgender people. To address the needs of transgender people living outside of major metropolitan areas, funding should focus on working with existing programs to better reach and serve clients living in more rural

We need our funders to give more money for transgender youth programs that address not only HIV but the co-factors that impact behaviors in this community.

 Transgender Harm Reduction Project of Children's Hospital, Los Angeles, CA

areas. Some possibilities include creating innovative, community based and structural interventions; supporting programs in building and sustaining a more visible presence on the internet; providing additional support/incentives for patients and clients needing to travel long distances to access services or bring services to communities (such as a mobile van for health screenings); and providing services and resources in multiple languages.

6. <u>Hiring and training transgender women in research and programming is necessary for programs</u> to succeed.

I facilitate trainings for transgender participants and invite other trans trainers from the community. Some of our trainings educate trans people to become outreach workers or peer counselors, so it works to give them more employment options.

 St. James Infirmary San Francisco, CA There is a high unemployment rate due to employment discrimination, and lack of job training and educational opportunities. Staff turnover creates a barrier to forming long-term relationships with clients and patients and leads to disruptions in services and impedes trust. Therefore it is critical to support staff development and adequately compensate employees to decrease turnover. Compensation should include medical benefits that are inclusive of transgender health care. In addition, creating paid internships and fellowships focused on transgender health are essential for building capacity in the field and engaging young professionals early in their career.

7. Funding should continue to reflect the HIV epidemic, with concentrated efforts on prevention among transgender women of color.

Communities of color represent disproportionately high numbers of new AIDS cases and comprise the largest number of people living with AIDS in the US (CDC, 2006). Race and ethnicity are not risk factors for HIV in and of themselves. Instead, they are markers for other factors that put people at higher risk for HIV, including limited economic resources and unequal access to

The HIV prevention needs of Latina transwomen are multi-layered and need to be addressed by a comprehensive, multifaceted prevention program.

- Bienestar Los Angeles, CA

health care. Many transgender women of color live in the urban epicenters of California (i.e., San

Francisco, Los Angeles, and San Diego) and while the funding should continue to reflect this, funding for transgender HIV prevention programs in other parts of California needs to be increased to provide adequate services to transgender people living in more rural areas.

8. There is a strong need for increased education, training and communication among providers.

Educating agencies that are providing HIV prevention services to other priority populations (i.e. MSM) about how to serve transgender clients who may seek services there (i.e., trans MSM). Transgender people need to be able to seek all types of health care without fear of discrimination based on gender identity or legal status. To be effective in serving transgender clients and patients, providers must be trained and updated on new HIV prevention trends to tailor their services and practice, better identify transgender individuals and their health needs, share educational information and best practices with other providers, maintain a transgender-friendly schedule, and build local capacity of and establish better linkages to mental health professionals.

Best Practices for Transgender HIV Prevention

The Best Practices for Transgender HIV Prevention are based on the information we have gathered about successful HIV prevention programs that currently exist in California. It is our hope that these Best Practices will strengthen the capacity of agencies that are looking to initiate or improve HIV services for transgender people to implement practices that have already been identified as successful. With access to existing knowledge and experience from thriving programs that already exist in California, we can build on previous learning experiences to efficiently utilize valuable time and resources. We believe that identifying, disseminating, and adapting Best Practices to local communities are vital steps to enabling an effective response to the HIV epidemic among transgender people in California.

These Best Practices assume a basic level of cultural competency in providing services to transgender people. Issues such as using appropriate language and pronouns to address transgender clients, creating forms that are inclusive of varying transgender identities, and creating a safe space for transgender people (e.g. safe and accessible restrooms) have been addressed elsewhere (41, 42). The Best Practices we offer here are specific guidelines for HIV prevention programs that are seeking to develop, expand, or improve services and programming for transgender clients.

I. Ground your work in the community.

Involving transgender community members has been an asset in getting a clear picture as to the diversity of the community and varying needs each segment of the community may have.

 Project STAR (Supporting Transgender Access to Resources)
 San Diego, CA Involve the community in program planning and implementation to ensure acceptability, appropriateness, and relevance of the intervention to the priority population. Evidence suggests that people are more likely to sustain changes when they are actively involved in bringing those changes about. Programs should be created with extensive participation and involvement of the transgender community. Involve transgender people at all levels of the program, especially those who are well-versed in the specific needs of the priority population. Peer educators and volunteers from the community are invaluable in ensuring community participation and relevance. In addition, provide mechanisms for the community to give feedback and ideas by creating a Community Advisory Board or holding community forums to help unify the program's mission and the community's vision for the program. Be responsive to the feedback you receive

from the community and be willing to change and be flexible in order to enhance your programs and services. Making sure your program and staff are consistently visible in the community builds trust and maintains rapport with clients. It's critical to prioritize collaborations with other programs and service providers to ensure that your knowledge is up to date of available services in the community and your referrals are helpful. Creating forums (in-person or via e-mail list serves) for networking with other service providers can be very useful in terms of sharing information, resources, and problem solving.

2. Race and ethnicity: One size does not fit all.

Incorporate racial/ethnic issues that contribute to HIV risk and issues of stigma and discrimination that are specific to transgender people into your program. This is especially important to keep in mind when adapting and translating interventions originally designed for other priority populations, such as women, MSM, and sex workers. Many of these interventions, because they were not originally developed for transgender people, let alone transgender people of color, do not address important risk factors unique to transgender communities. These risk factors may include needle sharing for injection hormones or silicone, or addressing additional life issues such as language barriers and lack of family acceptance, school and employment discrimination, and police violence due to transphobia.

Through formative evaluation, including focus groups and key informant interviews, we collected extensive data about the needs of Latina transwomen in Los Angeles and used this data to adapt and implement the SISTA intervention so that it addresses the linguistic and cultural needs of Latina transwomen.

- Bienestar Los Angeles, CA

3. Utilize multidisciplinary approaches to HIV prevention.

Educate and provide services and care through a broader context of health and wellness. Consider approaches that not only prioritize the individual, but also include their families, social networks, schools, communities, and organizations that transgender people live, work, and play in. For example, host events that include non-trans family members, partners, or friends. Building transgender people's support networks can help counteract isolation for both the clients and their loved ones.

Utilize multiple means of publicizing HIV testing and other services and activities, such as posting on popular internet sites (e.g. MySpace, Craigslist), We have a really great space and constant client base present. That has encouraged our collaborations because they know they can reach folks here. For us it is great to have outside folks come in because we can offer a wider range of services to our clients.

- TRANS: THRIVE San Francisco, CA

hosting harm reduction chats, and publishing newsletters. Work to make your publications accessible and relevant by having them available in multiple languages, provide up-to-date information on trans-specific resources, events, and prevention activities.

Create opportunities for empowerment through dialogue about the problems faced by the community and development of solutions. This can provide much-needed social support as well as an opportunity for individuals to move out of a sense of powerlessness and into a sense of strength through community.

4. Get the facts: Assess, evaluate and enhance.

Conduct thorough needs assessments and evaluations, and use the data in program planning and improvement. Focus your needs assessments and evaluations on data that is useful to your organization. Even when a full needs assessment is not feasible given the resources of the program, holding an open Community Forum provides an opportunity for transgender community members to

share their needs, concerns, and problems with the program staff. Disseminate information, especially on subpopulations where data is lacking. Integrate the evaluation data in a meaningful way. Request technical assistance.

5. Look in all the right places.

Consider the unique needs and circumstances of your priority populations when planning recruitment and retention strategies. Learn culturally appropriate outreach strategies for working with high-risk transgender women, many of whom are homeless, sex workers, and have mental health concerns. In conducting outreach, programs must make an effort to go beyond what is convenient. Outreach staff should bring information and services to the transgender clients in their community whenever possible. Sex workers tend to congregate in specific neighborhoods. It is important to determine where the people are and go to them.

We offer a range of programs that focus on overall well-being and quality of life, such as a cinema club, dances, and artistic performances (i.e. music, poetry, song, theater). Our clients have found the artistic performances are a healing and empowering way to face issues of suffering and trauma, as well as raise awareness in the broader community about the issues faced by Translatinas.

- El/La San Francisco, CA Combining education and entertainment can be an effective strategy to disseminate information and attracting participants. Artistic performances by members of the transgender community, pageants, balls, and other events, can serve as creative outlets as well as effective recruitment strategies and venues for HIV testing and prevention activities.

Retention can be difficult in areas where accessible and safe transportation is an issue. When possible, programs should situate themselves in areas where transgender women live and work. Other approaches to addressing transportation issues can include distributing bus passes and organizing events in popular, safe, and accessible venues for transgender clients. Use of incentives is important to encourage participation of populations who are highly marginalized in which their time is very limited due to survival needs and priorities.

6. Increase access to health care for trans people.

The biggest challenge that trans people face with regards to health care is access to culturally competent, affordable health care. This includes trans care and a lack of trained providers outside of most metropolitan areas.

Lyon Martin Health Services
 San Francisco, CA

Transgender people often find it difficult to navigate health care systems or find linguistically appropriate services. Provide support and follow-up on any referrals given. Make sure that transgender people in your area are fully aware of the programs and services that are available to them by marketing your services widely, developing resource guides, and posting flyers for other programs in your area.

In order to make your services more accessible for transgender people, you may have to build flexibility into your service provision, such as making evening appointments available or delivering services directly to your clients through a service van or other mechanism. Incorporating hormone

therapy into primary or HIV care services greatly increases access for many transgender people for whom hormones are a top priority.

7. Invest in developing and supporting your staff.

Many transgender women do not have extensive experience in the mainstream work force and need additional support and training. Staff turnover can be high due to demanding expectations and low pay. Emphasizing staff development can empower transgender women to then serve as role models for others.

Build in staff support mechanisms, such as a flexible work hours and team building, to increase staff retention. Organizational leaders should model commitment, passion, and teamwork. Be patient and put a lot of time and resources into staff development.
Empower disenfranchised transgender women and they will learn and grow and then empower themselves and one another.

TransAction
 Los Angeles, CA

8. Advocate for structural and systemic change on behalf of trans people.

Collaborate with community partners to advocate for policy development and social change to end institutionalized discrimination. Providers – not just transgender clients and patients – need to combat hostile policies and practices. Programs that serve MSM, especially young MSM, need to be educated about the diversity of transgender communities so that clients that use these services feel comfortable disclosing their true gender identity and risk behaviors. It's critical to crate change that is systemic and structural.

We advocated on behalf of the trans communities in our programming, addressing issues such as police brutality and criminalization of transwomen by working to end the targeting of trans female sex workers by police. We have as much reason as everyone else to be on the street.

 Instituto Familiar de la Raza San Francisco, CA Examples include: networking with legislature and policymakers to expand programs in your area; seeking resources and support for immigrants seeking political asylum; participating in service networks and local Department of Public Health planning committees; working for increased insurance coverage for transgender-related medical issues, legal consultation for transgender-related issues and transgender representation in public policy; working with city housing departments to improve the affordable housing crisis; working with local police to improve the working environment for sex workers and reduce police harassment; and advocating to change policies that limit the accessibility of syringes and syringe exchange programs and policies that prevent condom distribution.

References

- 1. Boehmer U. Twenty years of public health research: Inclusion of lesbian, gay, bisexual, and transgender populations. American Journal of Public Health 2002;92(7):1125-1130.
- 2. Clements-Nolle K, Marx R, Guzman R, Katz M. HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. American Journal of Public Health 2001;91:915-921.
- 3. Garafalo R, Deleon J, Osmer E, Doll M, Harper G. Overlooked, misunderstood, and at-risk: Exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. Journal of Adolescent Health 2006;38:230-236.
- 4. Nemoto T, Operario D, Keatley J, Villegas D. Social context of HIV risk behaviors among male-to-female transgenders of color. AIDS Care 2004;16:724-735.
- 5. Clements-Nolle K, Marx R, Katz M. Attempted suicide among transgender persons: The influence of gender-based discrimination and victimization. Journal of Homosexuality 2006;51:53-69.
- 6. Melendez R, Pinto R. 'It's really a hard life': Love, gender and HIV risk among male-to-female transgender persons. Culture, Health, and Sexuality 2007;9(3):233-245.
- 7. Lombardi E. Public health and trans-people: barriers to care and strategies to improve treatment. In: Meyer IH, Northridge ME, editors. The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual, and transgender populations. New York, NY: Springer; 2007. p. 638-652.
- 8. Meyer IH, Northridge ME, editors. The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual, and transgender populations. New York, NY: Springer Science and Business Media; 2007.
- 9. Diaz R, Ayala G, Bein E. Sexual risk as an outcome of social oppression: Data from a probability sample of Latino gay men in three US cities. Cultural Diversity and Ethnic Minority Psychology 2004;10(3):255-267.
- 10. Diaz R, Ayala G, Bein e, Henne J, Marin B. The impact of homophobia, poverty, and racism on the mental health of gay and bisexual Latino men: Findings from 3 US cities. American Journal of Public Health 2001;91(6):927-931.
- 11. Rodriguez-Madera S, Toro-Alfonso J. Gender as an obstacle in HIV/AIDS prevention: Considerations for the development of HIV/AIDS prevention efforts for male-to-female transgenders. International Journal of Transgenderism 2005;8:113-122.
- 12. Elifson K, Boles J, Posey E, Sweat M, Darrow W, Elsea W. Male transvestite prostitutes and HIV risk. American Journal of Public Health 1993;83:260-262.
- 13. Xavier J, Bobbin M, Singer B, Budd E. A needs assessment of transgender people of color living in Washington DC. International Journal of Transgenderism 2005;8(2/3):31-47.
- 14. Risser JMH, Shelton A, McCurdy S, Atkinson J, Padgett P, Useche B, et al. Sex, drugs, violence, and HIV status among male-to-female transgender persons in Houston, Texas. International Journal of Transgenderism 2005;8(2/3):67-74.
- 15. Herbst J, Jacobs E, Finlayson T, McKleroy V, Neumann M, Crepaz N. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. AIDS and Behavior 2007.
- 16. California Department of Health Services. California HIV counseling and testing annual report: January December 2003. . Sacramento, CA: Office of AIDS; 2006.
- 17. Nemoto T, Operario D, Keatley J, Han L, Soma T. HIV risk behaviors among male-to-female transgender persons of color in San Francisco. American Journal of Public Health 2004 94(7):1193-1199.

- 18. Kellogg T, Clements-Nolle K, Dilley J, Katz M, McFarland W. Incidence of Human Immunodeficiency Virus among male-to-female transgendered persons in San Francisco. Journal of Acquired Immune Deficiency Syndromes 2001;28:380-384.
- 19. Nemoto T, Luke D, Mamo L, Ching A, Patria J. HIV risk behaviors among male-to-female transgenders in comparison with homosexual or bisexual males and heterosexual females. AIDS Care 1999;11(3):297-312.
- 20. Rose V, Scheer S, Balls J, Page-Shafer K, McFarland W. Investigation of the high HIV prevalence in the transgender African-American community in San Francisco; 2003.
- 21. Reback C, Simon P, Bemis C, Gatson B. The Los Angeles Transgender Health Study: Community report. Los Angeles: University of California, Los Angeles; 2001.
- 22. Edwards J, Fisher D, Reynolds G. Male-to-female transgender and transsexual clients of HIV service programs in Los Angeles County, California. American Journal of Public Health 2007;97(6):1030-1033.
- 23. Zians J, O'Brien T. The San Diego County Transgender Needs Assessment Report. San Diego: Family Health Centers of San Diego; 2006.
- 24. Sevelius J. The transgender men's study: Preliminary findings. In: US Conference on AIDS. Palm Springs, CA; 2007.
- 25. Kenagy GP, Hsieh CM. The risk less known: Female-to-male transgender persons' vulnerability to HIV infection. AIDS Care 2005;17(2):195-207.
- 26. Xavier J, Bradford J. Transgender health access in Virginia: Focus group report: Virginia Department of Health; 2005.
- 27. Sugano E, Nemoto T, Operario D. The impact of exposure to transphobia on HIV risk behavior in a sample of transgendered women in San Francisco. AIDS and Behavior 2006;10:217-225.
- 28. Sausa L, Keatley J, Operario D. Perceived risks and benefits of sex work among transgender women of color in San Francisco. Archives of Sexual Behavior 2007.
- 29. Sausa L. Translating research into practice: trans youth recommendations for improving school systems. Journal of Gay & Lesbian Issues in Education 2005;3(1).
- 30. Operario D, Burton J, Underhill K, Sevelius J. Men who have sex with transgender women: Challenges to category-based HIV prevention. AIDS and Behavior 2007.
- 31. Clements K, Wilkinson W, Kitano K, Marx R. HIV prevention and health service needs of the transgender community in San Francisco. International Journal of Transgenderism 1999;3(1 + 2).
- 32. Newfield E, Hart S, Dibble S, Kohler L. Female-to-male transgender quality of life. Quality of Life Research 2006.
- 33. Hussey W. Slivers of the journey: The use of photovoice and storytelling to examine female to male transsexuals' experience of health care access. Journal of Homosexuality 2006;51(1):129-58.
- 34. Melendez R, Exner T, Ehrhardt A, Dodge B, Remien R, Rotheram-Borus M, et al. Health and health care among male-to-female transgender persons who are HIV positive. American Journal of Public Health 2005;95:5-7.
- 35. Holtgrave DR, Anderson T. Utilizing HIV transmission rates to assist in prioritizing HIV prevention services. In; 2004. p. 789-792.
- 36. Woods T, Carver L. State of emergency: HIV and other health threats among transgender women in Alameda County; 2007.
- 37. Bockting W, Robinson B, Forberg J, Scheltema K. Evaluation of a sexual health approach to reducing HIV/STD risk in the transgender community. AIDS Care 2005;17:289-303.
- 38. Nemoto T, Operario D, Keatley J, Nguyen H, Sugano E. Promoting health for transgender women: Transgender Resources and Neighborhood Space (TRANS) program in San Francisco. American Journal of Public Health 2005;95 (3):382-384.
- 39. Nemoto T, Sausa L, Operario D, Keatley J. Need for HIV/AIDS education and intervention for MTF transgenders: Responding to the challenge. Journal of Homosexuality 2006;51(1):183-202.

- 40. McKleroy VS, Galbraith JS, Cummings B, Jones P, Harshbarger C, Collins C, et al. Adapting evidence-based behavioral interventions for new settings and target populations. AIDS Education & Prevention 2006;18(4):59-73.
- 41. Sausa L. Best practices for health service organizations to improve programs and services for trans clients and patients. In; 2007.
- 42. Long M, Gortner C. The Transgender HIV Health Services Best Practices Guidelines. San Francisco, CA; 2007.

Appendices

Summary table of Transgender HIV Prevention Programs in California

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Resource Inventory Program Questionnaire

** Please return this completed form within 1 to 2 weeks. We appreciate your responsiveness and look forward to highlighting your program in our Compendia!

Program Contact and Services Information

Program Contact and Services Information
The following information will be visible on our website's list of California programs.
Name of Host Organization:
Host Organization Address, City, State, and Zip:
Name of Transgender-Specific Program:
Program Address, City, State, and Zip (if different from host organization):
Program Phone Number:
Program E-mail Address:
Program Website Address:
Specific Services Available: (i.e, HIV and/or STD testing, Clinic services: medical check-ups, vaccinations, gynecological exams; peer counseling, professional mental health services, housing assistance, job placement, services in various languages, training, speaker panels, case management, drug and alcohol recover services, etc):
Primary Contact Person Name:
Title:
Office Address:
Phone:
E-mail:

Programmatic Profile Information for Compendia

The following information is for <u>compilation purposes only</u> and will not be visible on our website. This information will be integrated with information from other programs to inform various reports on the current programming available to transgender people across the state of California.

Not all sections will be applicable to your program; in these cases, please type N/A. For sections pertaining to needs assessments, evaluations, and other types of reports that you may wish to contribute to the Compendia, you may attach those documents and skip those sections.

As soon as we receive your questionnaire, we will schedule a call you to follow-up on your responses and clarify any points of interest. If you wish to answer any of these questions by phone instead of filling them out electronically, feel free to skip those questions and we will record your responses when we talk by phone.

Host Organization: This section includes questions about your organization as a whole, not specific to the transgender program.

- 1) What is the mission (or goals) of your host organization?
- 2) What services does your organization provide?
- 3) What priority populations does your organization serve?
- 4) What is the total host organizational funding budget?
 - i) What are the funding sources?
 - ii) What is the breakdown/percentages?
- 5) What is the number of staff in your host organization?
- 6) Have you had any trans-specific training at your organization?
 - i) When was the last one provided?
 - ii) Who provided the training?
 - iii) What were the goals or learning objectives of the training?
 - iv) Where these goals or learning objectives accomplished?
 - v) Did you attend the training?
 - vi) If so, do you think it was it helpful in advancing your organization's capacity to work with trans people?

vii) Do you think it was it helpful in helping your organization be a better work environment for trans staff members?

Transgender-Specific Program

- 7) What priority populations does your trans-specific program serve?
- 8) How do people access your services? (i.e. through outreach, internet, referrals)
 - i) Has your programs produced any transgender-specific social marketing materials (i.e. brochures, posters, PSAs)?
- 9) What is the funding budget for your trans-specific program?
 - i) What are the sources of funding?
 - ii) What is the breakdown/percentages?
- 10) What is the number of staff for your trans-specific program?
 - i) Are they paid full time staff, part-time staff, and/or volunteers? What are their positions?
 - ii) What are their demographics? (i.e. How well are different ethnic groups and gender identities represented among your staff?)
 - iii) Are any staff trans? If so, are they out as trans?
 - iv) How long has current staff been in their positions?
- 11) How many transgender clients do you serve on a weekly basis?
- 12) What is the mission (or goals) of your trans-specific program?
- 13) When and how did the trans-specific program begin?
- 14) What were some of the barriers and facilitators to implementing a trans-specific program in your organization?
- 15) Are (or were) there any community partners or collaborators involved in the development and/or implementation of your program?
 - i) If so, what have been the barriers and facilitators to successful community collaborations?
- 16) Describe the challenges you have encountered in hiring and retaining staff.
- 17) Describe the challenges you have encountered in recruiting and retaining clients.

i) Are there any segments of the population that you are not currently reaching?

Program Assessment & Evaluation: In this section we hope to get some information about how your program began, what data you have collected (or plan to collect) in your community, and how you are currently evaluating your program.

- 18) Is your trans-specific HIV prevention program based on an EBI (Evidence-Based Intervention)? If so, which one?
 - i) Can you describe how you chose the EBI and why?
 - ii) Can you describe the adaptation process?
- 19) Have you conducted any transgender community needs assessment (or any other types of needs assessment) for program planning purposes? (If you have a needs assessment report you will attach, you may skip this section.)
 - i) When did you conduct it?
 - ii) What methods did you use (survey, interviews, focus groups, etc)?
 - iii) Did the needs assessment inform the development of the trans-specific program?
 - iv) What did you find out about the needs of trans people in your area?
 - v) Do you have a written report you could share?
 - vi) Did the needs assessment highlight any specific risk factors, new health issues/concerns, or trends among trans people? If yes, please explain.
 - vii) What did you learn about the needs of transwomen in particular?
 - viii) What did you learn about the needs of transmen?
 - ix) What did you learn about the needs of youth?
- 20) Have you or are you currently evaluating the trans specific program? If so, please describe your current evaluation plan. (*If you have an evaluation plan or report you will attach, you may skip this section.*)
 - i) What resources do you have in place to devote to evaluation? (i.e. funding, staff)
 - ii) What data collection methods are you using?

- iii) How do you ask for and receive feedback from your participants? How do you monitor the process of implementing your program?
- iv) What have you found from your evaluation? Do you have any reports you could share?
- v) What, if anything, have you enhanced or changed because of the evaluation process?

Lessons Learned, Challenges, and Emerging Issues: We are looking for programs and community leaders that exemplify the best practices in HIV prevention for transgender communities. This section is your opportunity to share with us the various ways that you and/or your program excel in doing this work.

21) Based on your professional experience what are some best practices you would like to share with health providers working with trans people? What do you feel your program does really well? Why?

Follow up on any strong points previously raised, such as:

- Recruitment & retention
- Collaborations
- Community and/or client involvement in program design, implementation, evaluation, education, outreach, social marketing, etc.
- Building referral networks
- Health care services
- Other resources in area (substance abuse treatment, housing, etc.)
- Client advocacy
- Harm reduction
- Program evaluation
- 22) Please describe the lessons you have learned from doing this work.
- 23) Describe the challenges you have encountered along the way and how you have addressed them.
- 24) What are the biggest challenges that trans people in your community face with regards to health care and HIV prevention and care today?
 - i) Do you have any recommendations for addressing these challenges?
- 25) Can you refer us to other trans-specific HIV prevention programs in California that you know of?

26) We are currently recruiting a new youth member for our Center of Excellence Community Advisory Board. Do you know a youth under 24 that you could recommend for this position?
Thank you for your time! Please email, fax, or send this form to us with any attached documents as soon as possible and we will schedule a call to follow-up with you.
Documents attached:

ATTACHMENT H: EXAMPLE OF AN EVALUATION

Meeting Evaluation

1)	Where	the objectives for this meeting clear and accomplished?
		Yes
		No
		Other: Please Explain which objectives weren't met:
2)	Was th	is meeting useful?
		Yes
		No
		If "No", what could've been done differently?
3)	Did yo	u learn anything new during this meeting?
		Yes
		No
		If "Yes", what did you learn?
4)	Did the	e facilitators seem to keep the group on track?
		Yes
		No
		If "No", what could they have done differently?
5)	Was th	e atmosphere friendly, cooperative, and pleasant?
		Yes
	П	No

		If, "No", what could be done differently to create a safe environment?
6)		you recommend the coalition to any of your peers, allies or ntances?
		Yes
		No
		If "No", why not?
7)	Do you	have any additional comment you'd like to include?

Thank you for your feedback! We will make every effort to ensure that we improve based upon your feedback.

ATTACHMENT I: EXAMPLE OF A COALITION-DRIVEN NEEDS ASSESSMENT

ACCESS TO HEALTHCARE AND HIV PREVENTION SERVICES SURVEY

DEMOGRAPHIC INFORMATION

1.	What is your current gender?										
	□ Male □ Female □ TransMale/Transman/FTM □ TransFemale/Transwoman/MTF □ Genderqueer □ Additional Category (Please Specify): □ Decline to State										
2.	What sex were you assigned at birth?										
	□ Male □ Female □ Decline to State										
3.	What is your sexual orientation? Please select all that apply.										
	☐ Queer ☐ Gay ☐ Questioning ☐ Lesbian ☐ Bisexual ☐ Heterosexual ☐ Decline to answer ☐ Other, please specify:										
4.	What is your ethnicity or race? Please select all that apply.										
	□ Asian or Asian American □ Black or African American □ Middle Eastern □ Multiracial □ Other, please specify: □ Pacific Islander □ Pacific Islander □ Native American □ White/Caucasian □ Decline to answer										
5.	What language do you speak most frequently at home? Please select all that apply.										
	\square English \square Spanish \square Vietnamese \square Tagalog \square Other (specify):										
6.	Are you Bilingual? □ Yes □ No										
7.	What is your age?										
	\Box 18 to 24 years old $\ \Box$ 25 to 29 years old $\ \Box$ 30 to 39 years old										
	\square 40 to 49 years old \square Over 50 years old \square Decline to answer										
8.	Which county do you live in?										

9. What city do you live in?										
EMPLOYMENT AND INSURANCE										
10. Are you currently employed? Please select one.										
☐ Yes ☐ No ☐ Other, please specify:										
11. Have you exchanged any form of sex for m	oney in the l	ast 6 months?								
\square Yes \square No \square Not sure, please (If "No" skip to	13)									
12. Have you had to use that money in order to the last 6 months?	o be able to a	fford healthca	re services in							
☐ Yes ☐ No ☐ Not sure, please specify:										
13. Do you have health insurance? \square Yes \square No										
14. If YES, what kind of health insurance do yo item below.	14. If YES, what kind of health insurance do you have? Please answer "yes" or "no" to each item below.									
 Insurance through work. COBRA or OBRA Private insurance/HMO, not through and the second of the second o	work	Yes No								
7. County-funded program 8. Private pay/out of pocket/fee for serv 9. Other (please specify): HEALTHCARE SERVICES		-								
15. How much do you think each of the following factors present barriers for you when needing to see a doctor, nurse or other healthcare provider? Please check the box beside the statement that most describes your experience.										
	Not at All	Somewhat	Very Much							
1. Location of services.										
2. Days and hours of operation										
3. Having to disclose your gender identity										
4. Concerns about confidentiality										
5. Lack of health insurance										
6. Cost of services										
7. Feeling uncomfortable talking about sex or sexuality										
8. Providers that are uneducated about										

transgender healthcare needs

9. Past experience with discrimination because of

 16. Hav	e you acc	cessed trans incl	usive healthc	are services i	n the last 12 m	onths?
□ Y	es 🗆 No	□ Don't know				
17. Are	you awa	re of trans inclu	sive healthcar	e services in	your area?	
\Box Y	es 🗆 No	□ Don't know				
	es please l n:	ist				
PREVE	NTION A	ND CARE SERVIC	CES			
18. Hav	e you acc	cessed trans incl	usive HIV pre	vention servi	ces in the last 1	2 months?
□ Y	es 🗆 No	□ Don't know				
19. Are	you awa	re of trans inclu	sive HIV prevo	ention service	es in your area?	•
\Box Y	es 🗆 No	□ Don't know				
	es please l m:	ist				
	e you aco	cessed trans incl	usive HIV/AII	OS healthcare	services in the	last 12
$\Box Y$	es 🗆 No	□ Don't know				

your gender identity

21. How much do you think each of the following factors present barriers for you when needing to see a doctor, nurse or other healthcare provider?

Please check the box beside the statement that most describes your experience.

	Not at All	Somewhat	Very Much							
1. Location of services.										
2. Days and hours of operation										
3. Having to disclose your gender identity										
4. Concerns about confidentiality										
5. Lack of health insurance										
6. Cost of services										
7. Feeling uncomfortable talking about sex or sexuality										
8. Providers that are uneducated about transgender healthcare needs										
Past experience with discrimination because of your gender identity										
10. Lack of professional support to help navigate the healthcare system										
healthcare services in your area? □ Yes □ No □ Don't know If Yes please explain:	□ Yes □ No □ Don't know									
23. How do you think local service providers of programs?	23. How do you think local service providers can improve their trans inclusive programs?									
24. Do you know if local HIV prevention and c □ Yes □ No □ Don't know If yes please explain:	are planning	efforts are trar	ns inclusive?							



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