Stigma and Access in Three Low-Resource Settings: HIV Training & Capacity Building Needs

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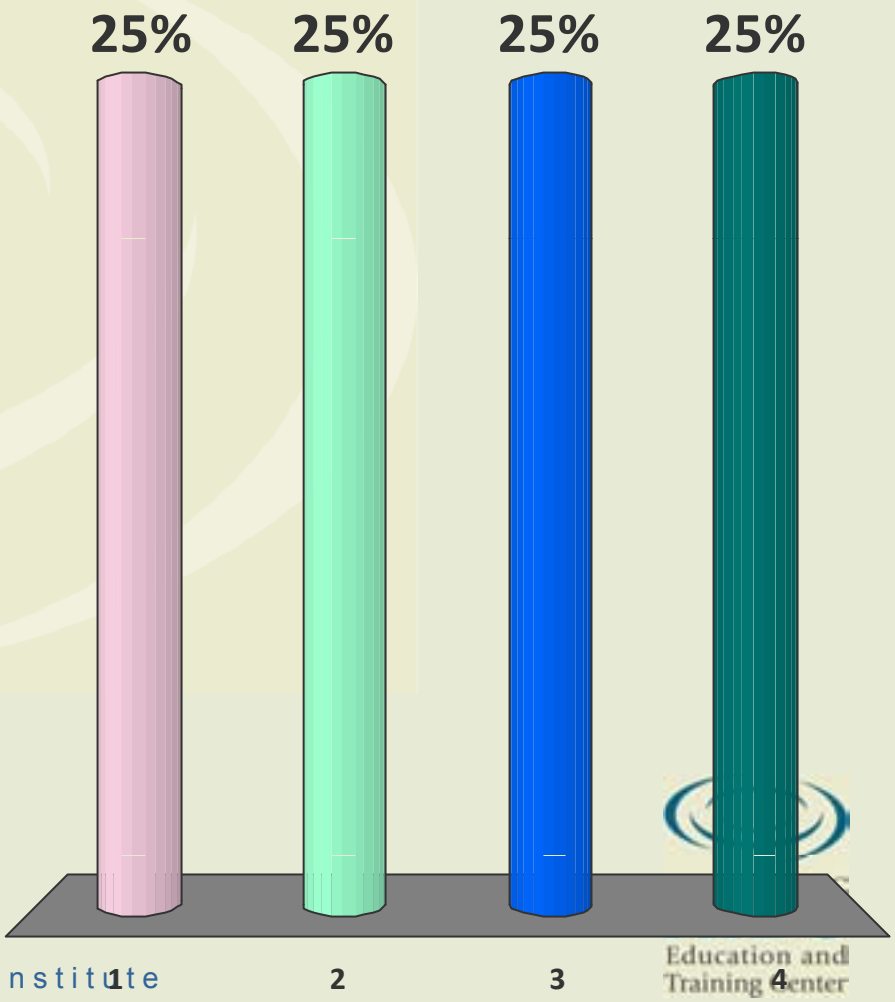
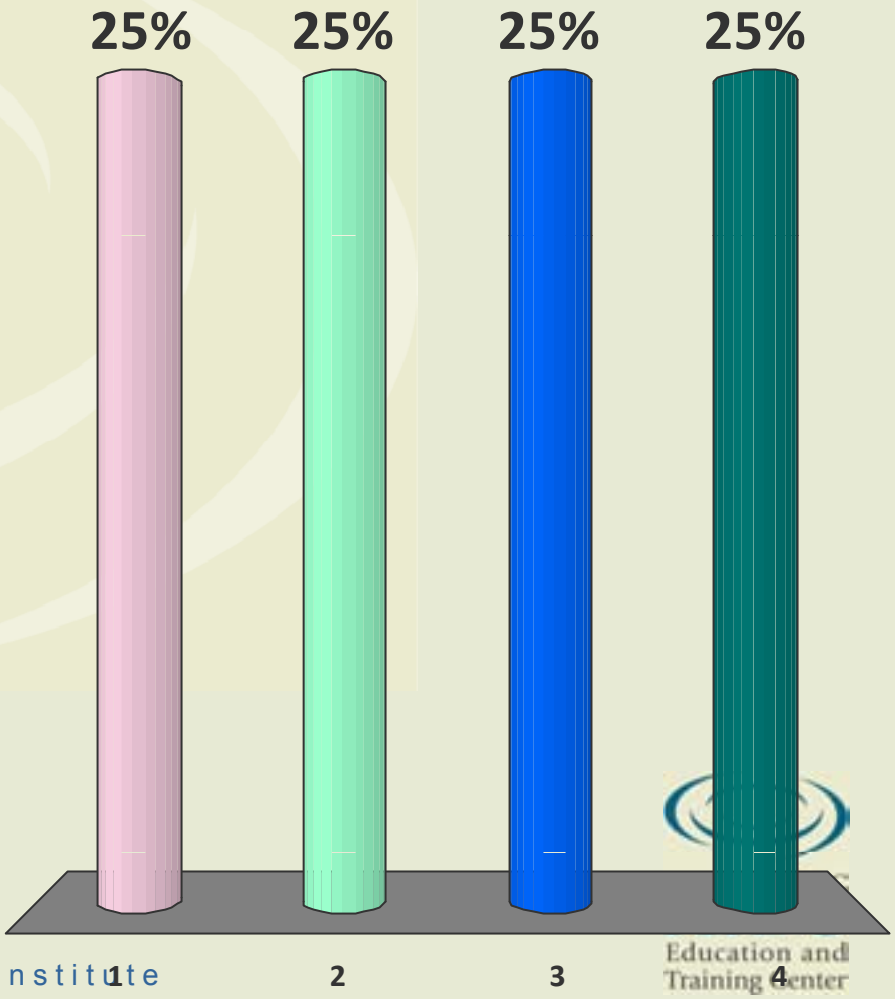
Would you say your practice or clinic is

1. High Volume
2. Medium Volume
3. Low Volume
4. N/A



I work in a high resource setting

1. Strongly Agree
2. Agree
3. Disagree
4. Strongly Disagree

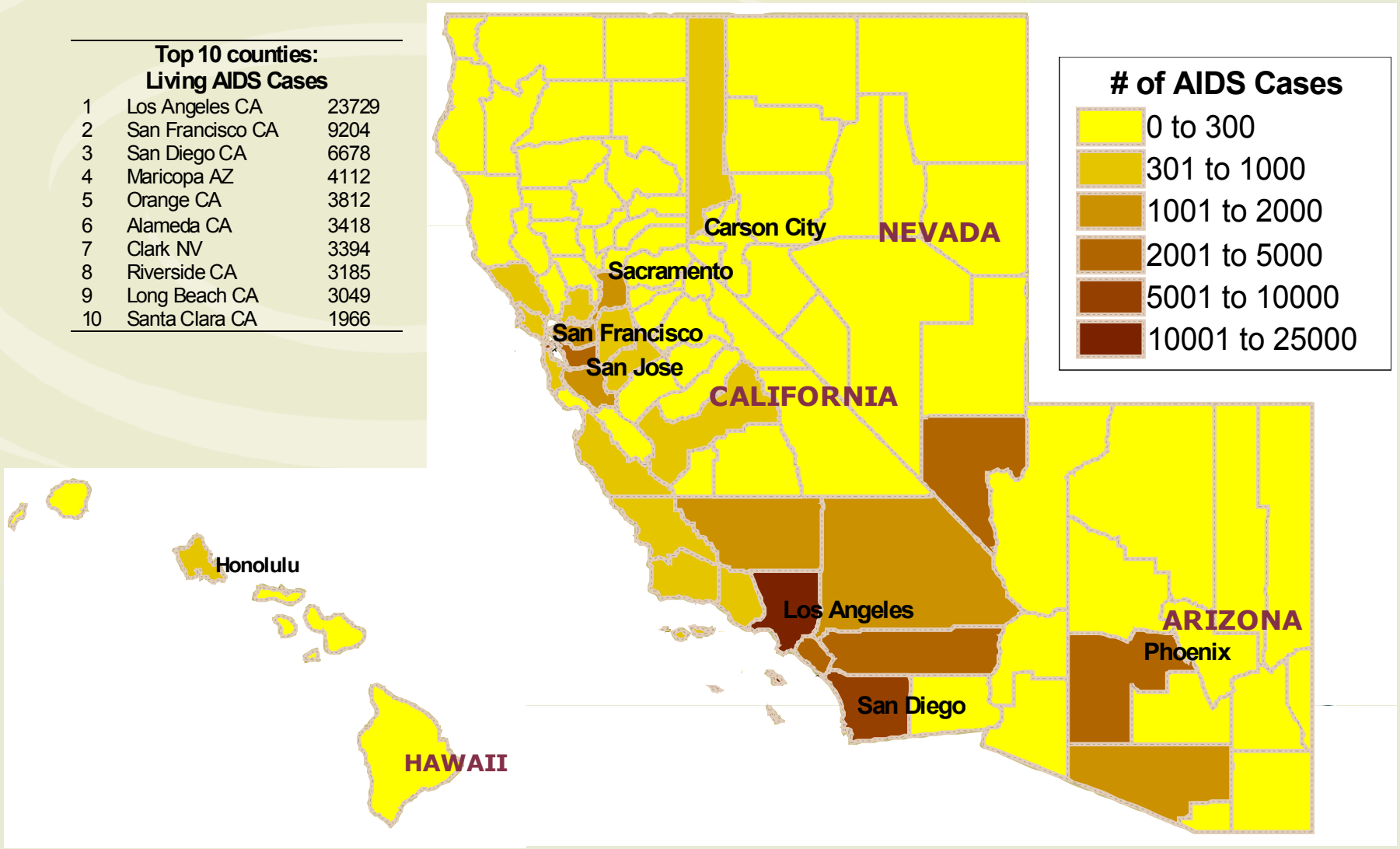


Methodology

- 3 Focus groups
- Conducted before/during conferences in 3 low resource settings in June 2010:
- Central Valley, CA (Fresno, CA)
- CA/AZ border region (El Centro, CA)
- Pacific Jurisdiction (Honolulu, HI)

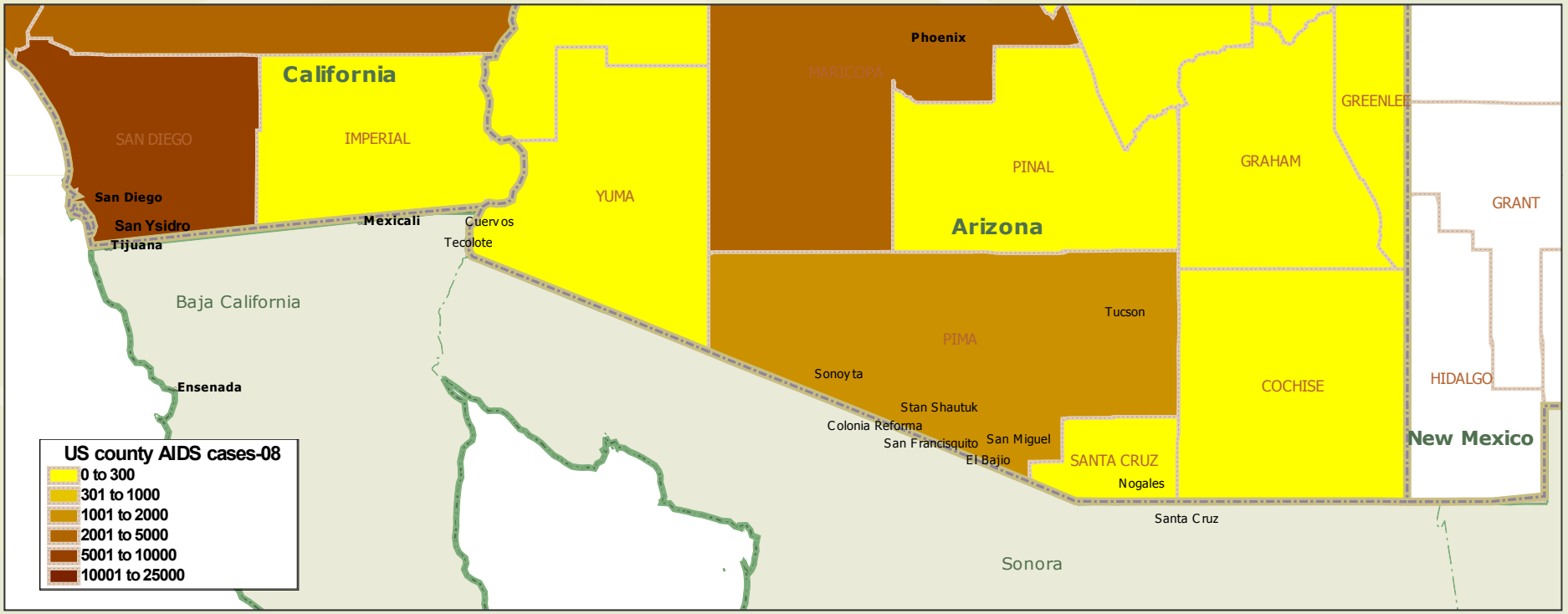
PLW AIDS: PAETC region (2008)

	Top 10 counties: Living AIDS Cases	
1	Los Angeles CA	23729
2	San Francisco CA	9204
3	San Diego CA	6678
4	Maricopa AZ	4112
5	Orange CA	3812
6	Alameda CA	3418
7	Clark NV	3394
8	Riverside CA	3185
9	Long Beach CA	3049
10	Santa Clara CA	1966



PAETC Pacific Jurisdiction

PAETC Border Region



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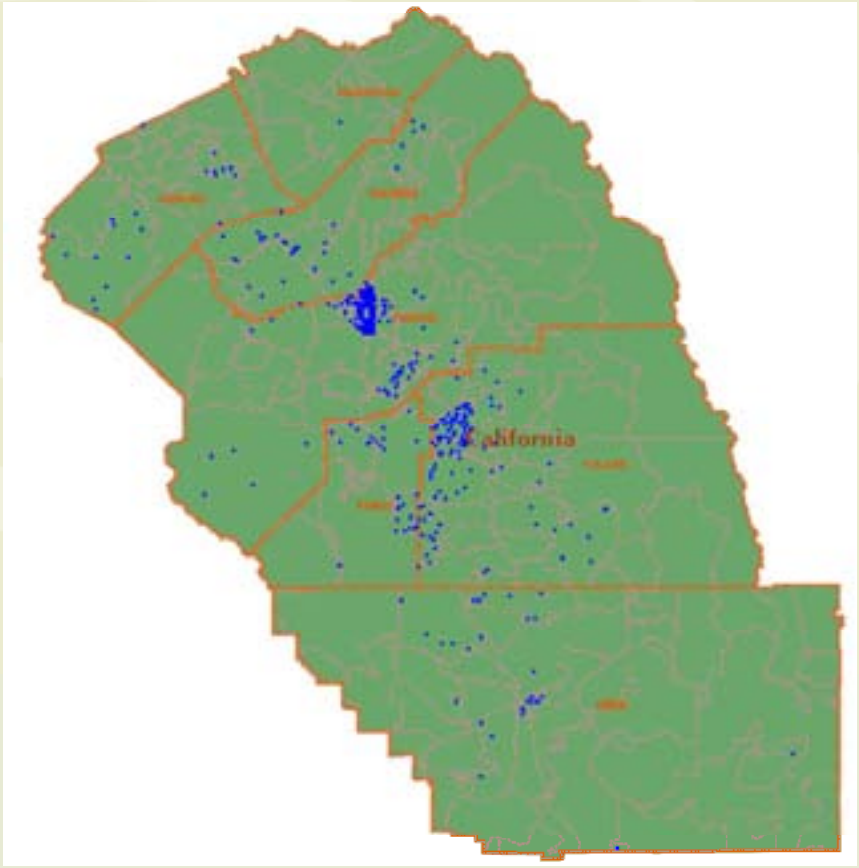
Central Valley



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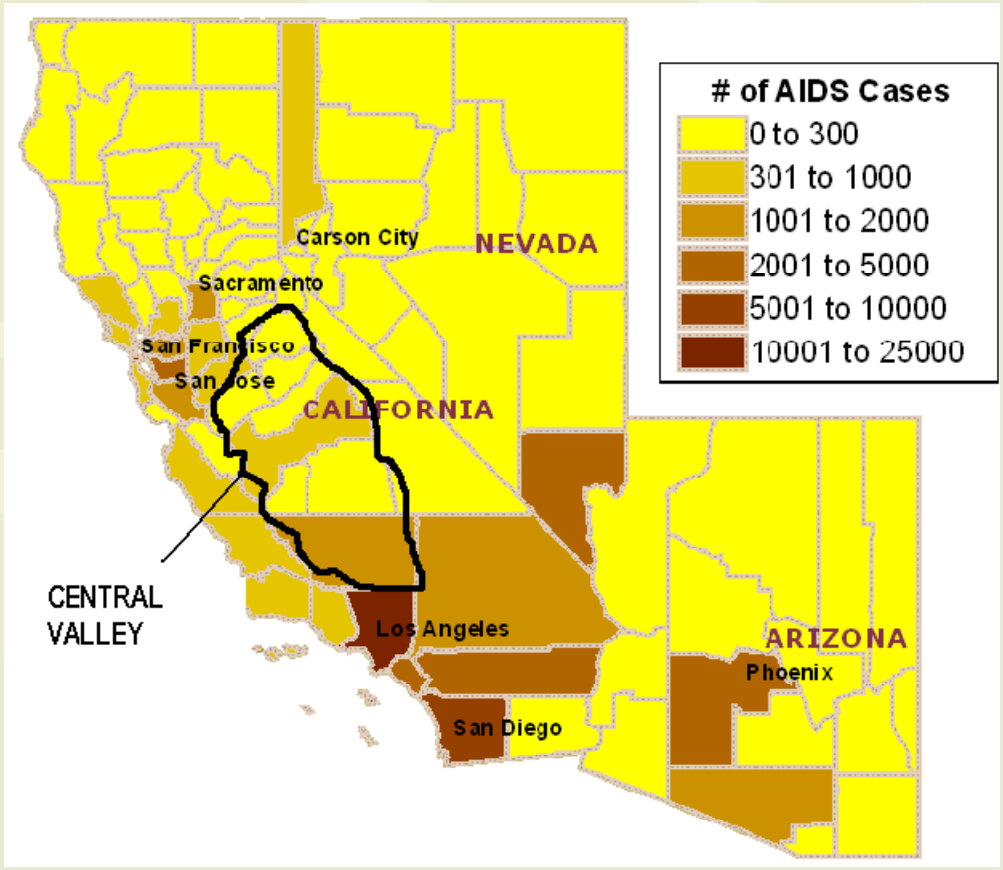
PAETC – CUTOUT OF THE CENTRAL VALLEY



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Focus group participants

- Doctors (HIV specialists and primary care MDs)
- Nurses (range from RNs to LPNs to NPs)
- Substance abuse counselors
- Patient advocates
- Community Health educators

Care Settings

- Health departments
- Non profit clinics
- Substance abuse treatment facilities

Specialty areas

- HIV
- TB
- STDs
- HEP C
- Substance abuse
- General primary care

Themes

- Stigma
  - -- Pt/Community level
  - -- Provider level
  - -- related more generally to sexuality

Themes

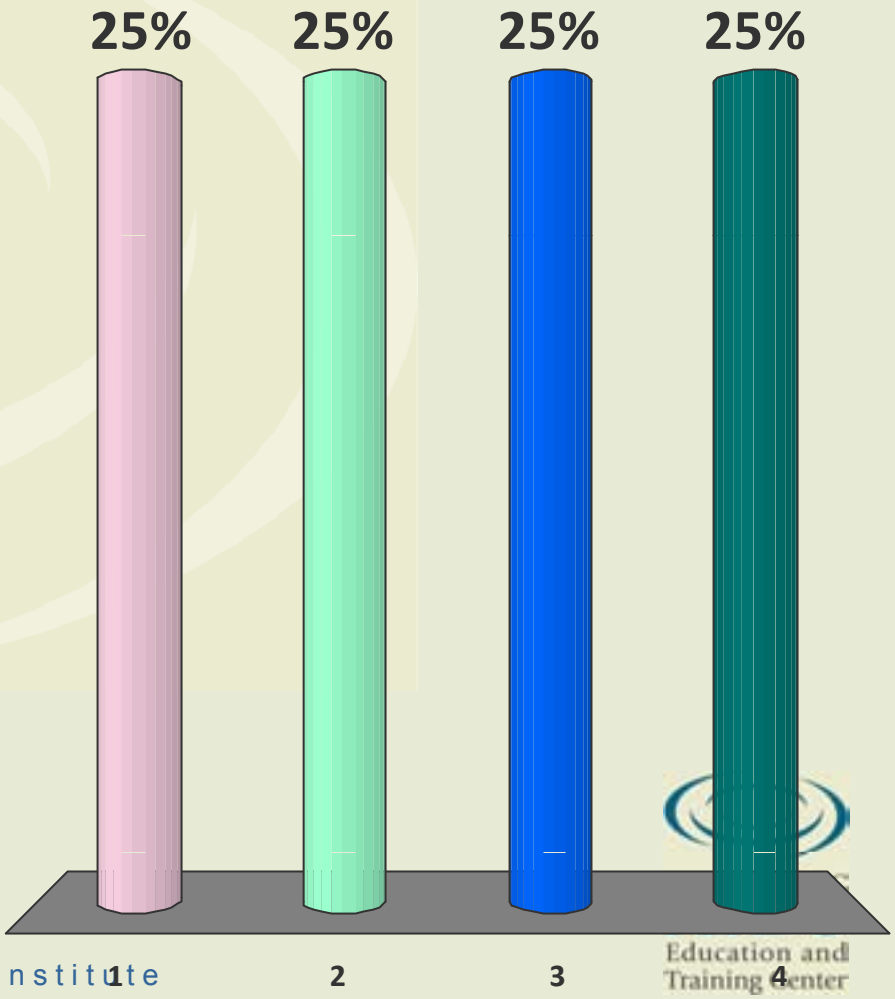
- Lack of resources –
  - Provider level (program and personnel cuts)
  - Patient level (service cutbacks, unemployment, foreclosure)
- Lack of linkage and communication

Themes

- Clinicians need education around screening and treating HIV, TB, Hep C, and Syphilis
- The entire clinic setting needs HIV training to decrease patient stigma and mainstream HIV
- With budget cuts the increased need for onsite or tele-education

Stigma prevents my patients from getting HIV tested or f/u care

1. Strongly Agree
2. Agree
3. Disagree
4. Strongly Disagree



Stigma- patient level

Focus group participants viewed stigma as widespread among patients, reflecting community norms, across all three settings at every potential HIV care point:

- Prevented people from getting an HIV test
- Prevented HIV+ people from seeking care
- Caused HIV infected people in care to not want to disclose their status

Stigma – rural, low resource setting

- *[stigma] …is a big part of it because they feel like they could lose family, friends -Their jobs, all of that, yeah, and it might be a lot different in more of an urban area or where it is more kind of out and people aren't as afraid and maybe it's not stigmatized as a disease that only people that do bad things {get}.*

  --Border area clinician

Stigma, limiting access to care

Fear of stigma is more important than, you know, viral load. For some people.

--Central Valley provider, nonclinician

…after all this time, I still have to - I don't mind - take the prescription, go to the pharmacy, get the drugs, come back and give it to the patient

--Pacific Island physician

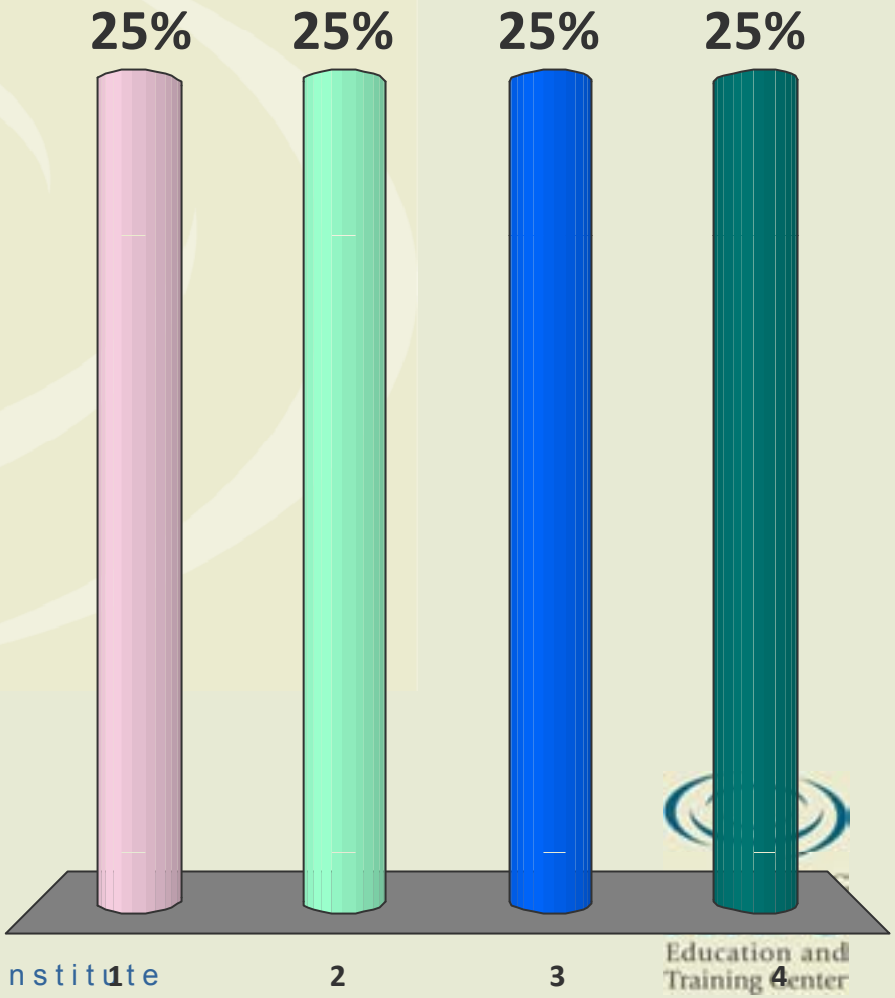
Stigma reflects larger taboo around sexuality including STIs

"…we will have clients that will walk in for chlamydia and gonorrhea, and we will offer them family planning. I mean, that's just a given. And they'll say, 'Oh, no, I go to my private doctor for that, but I'd rather come here to get this, because I know that if there's something there, then nobody will find out about it.' "

--Central Valley area clinician

Stigma prevents providers in my area from testing or treating HIV

1. Strongly Agree
2. Agree
3. Disagree
4. Strongly Disagree



Stigma - providers

Many providers in these localities tended to mirror their communities

- Discomfort asking about risk/HIV testing
- Discomfort being known to serve “those people”
- Not wanting to serve the population not necessarily because they are perceived to be gay, but perceived to be difficult, i.e. drug users, or multiply affected patients for whom the MD will not receive adequate compensation

Low volume clinician reluctance to HIV test

….it's the job of the primary care doctors to educate our patients to test - and people are not doing that - a lot of the older doctors still feel uncomfortable about talking about HIV, so if the doctor's uncomfortable with talking about HIV, they really think their patient's going to accept HIV? it's all about being comfortable…

-- Border area clinician

Providers: Reluctance to discuss sexuality

It's not just talking about HIV, I think talking about sexuality, anything sexuality related and then when you have something that has this stigma associated with it, it makes it even harder, I think, for the physicians to broach the subject.

--Border area clinician

Clinicians: lack of adequate payment for patient complexity

One of the problems with treating HIV as a provider is that you don't get adequately paid for the time that it takes. If you just deal with the HIV itself, it's a very complicated thing to deal with, and you throw in substance abuse issues and you throw in mental health issues or whatever, then it's like, boy, we've lost a bundle on that visit.. even if they have Medi-Cal, or payments or whatever …Frequently, it's the same {payment}…as if you saw a 16-year old with a sore throat!

-- Central Valley clinician

Stigma in TB as well

We have a lot of stigma in the TB {area} too...nurses {who see a tb patient} will say "Oh, I have to send my clothes out or I'll take it home to my kids" - it's education, education but sometimes they still don't get it. Even doctors don't get it.

Border area clinician

Lack of resources: providers' clinics/agencies lose staff

- many providers had lost up to half their personnel
- agencies cuts had resulted in providers inheriting other divisions or patient loads resulting in increased responsibility for more pts and diseases yet no time for training
- In cases where county HIV clinics for example or STD clinics had either been completely or radically cut, this led patients to move to other counties for treatment.

Budget cuts: ancillary staff

I think another unfortunate thing is that when the big state up in the sky does the cuts, they always think of cutting out the ancillary staff. So, the social worker…the nutritionist, the health educator and yet those are crucial positions, especially with the care of HIV patients, because there's that medical component, but then there are those other factors…

--Central Valley clinician

Lack of money and time for training

We had a lot of trouble getting approved to attend this training due to our budget cuts and the economy …but with the type of diseases that we work with, I feel like we need updated, we need something that we get like the latest, the updates but it was really hard to get approved…{before} we had three or four programs a year that we attended

-- Border Area Clinician

Patients lack of resources

- Patients have lost resources bc of provider cutbacks in cash aid, medical care hours, and medical benefits
- Undocumented patients often do not qualify for services or fear accessing services
- Patients have also suffered loss of resources due to unemployment, and foreclosure

Patients lack of resources benefit cuts

And if you look at the Medi-Cal cuts, too, in the last six months--they've lost dental. They've lost vision. They've lost podiatry. They've lost a lot of specialty services…I have a client right now, the surgeon is refusing to do surgery because she has loose teeth. And she has no dental. So, I'm kind of having to scramble, um, you know, to try to figure out how to get this done so that she can have her surgery.

--Central Valley Clinician

Patients lack of resources: the economy

…because of {unemployment}, the housing boom {gone bust} and people losing their homes, we have no work for these people, these people, of course, they cannot afford insurance and then they go to …{a clinic that} gives them sliding scales they cannot afford so we have a high also hospitalization rate on those groups…

--Border area clinician.

Lack of linkage and communication

- Linkages suffered because as programs were cut, referrals were quickly out of date
- Providers had less time to network with each other due to budget cuts
- Providers identified increases in syphilis in all their counties, leaving them wondering if they had an area epidemic

Lack of linkage and communication:

…the services, like we're saying, have been cut more than half. You get a client that comes in …and they've been turned away or pushed out the door, and you're thinking, 'Okay, this is what we're going to do.' And you get on the phone. I have a long list of services…to this, to that…And you know what? A lot of them are just closed.

-- Central Valley provider, nonclinician

Lack of linkages and communication

Patients in response, have become more mobile due to the budget cuts:

I was just going to say, and this has been since November of last year that we have seen an increase in clients that have come from the 2 neighboring counties. Just something that we had not seen in our clinic in awhile, which is syphilis. -- Central Valley clinician

Lack of linkage and communication

And so, we know that there's a cluster of {syphilis in} MSM…and now its spread to the female population. So you know Highway 99 is very fluid…people travel up and down there are no borders..It's not Fresno county, it's not Kings county…it's high way 99

-- Central Valley Clinician

Clinicians need training in HIV, TB, Hep C and Syphilis

- Participants stated examples of the need for clinicians in their area (including themselves) to have more education around screening and treating HIV, TB, Hep C and Syphilis
- Providers asked questions within the groups such as “are there national guidelines for treating HIV”? For Hep C testing?

Training and Education solutions:

- Continuing to education even when clinicians continue to resist
- Training personnel at all levels in the institution – so the atmosphere is normalized related to HIV+ clients
- Using distance learning or onsite education
- Address stigma as part of education

Educate providers to mainstream HIV

- The other doctors always get annoyed with me {discussing HIV} because they always say HIV is not important, talk more about myocardial infarction and diabetes…

  -- Pacific Islands clinician

- Increase awareness among health care workers so that we can normalize, (so it's) just like seeing a Hepatitis B case where we can write a prescription and send the patient to get medication

  -- Pacific Islands Clinician

Distance learning or onsite training

- *if somebody came to us we could get fifteen or twenty people educated at a time rather than just two of us (attending this training)…*
- *…with the schedules and things people can't leave with the shifts and they can't travel, I think it's actually either good to go there and teach or present it online like the internet.I think that's an excellent way to do it, it's exactly what we need - it's less expensive … and the staff …can't travel or leave but they maybe they can .take some time to go to {an in house] training ….*

--Border area clinicians

Tele-education/telemedicine

I think we need to explore the concept of telemedicine. Because I think that maybe if I knew that I could call this magical number that it would provide me with the answers. And I wouldn't have to share my information or where I'm coming from..How I'm looking at it is, if I'm a provider, and a client comes into my clinic, and I don't know what to do with it, then I should be able to speak to someone that's going to help me.

--Central Valley Clinician

Thank you

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