CAG Meeting Minutes
September 24, 11:00-3:00pm
White River Junction, VT
Facilitator: Daniel Daltry

Attending: Roy Belcher, Susan Bell, Mike Bensel, Laura Byrne, Daniel Chase, Sue Conley, Chris Fletcher, Kim Fountain, Jonathan Heins, Peter Jacobson, Chuck Kletecka, Debra Kutzko, Karen Peterson
Nora? ___, Mary? ___,
On the Phone: Grace Keller and Vanessa Melamede Berman; Erin LaRose, VDH
Organizations Represented: ASPV, RU12, PWA Coalition, CCC, H2RC, Vermont CARES, Safe Recovery

Vermont Department of Health: Daniel Daltry, Hannah Hauser
Center for Health and Learning: Alex Potter, Recorder

I. INTRODUCTIONS: Meeting convened at 11am with introductions.

- **COMMUNITY FEEDBACK:** *"HIV Testing, Linkage to Care in Vermont"*

II. VDH CURRENT TESTING PROGRAMMING

A. Daniel touched on the major changes in testing over the years – the arc from 1983 and the first test to today, with the advent of home testing.
   a. Now VDH is being asked by CDC to narrow the target of people tested, and to reach "1% positivity" with all testing efforts. The 1% standard applies to everyone the same, whether it be Florida, California or Vermont.
   b. Vermont is at 7 new HIV positives this year – a little ahead of the curve for Vermont, which is concerning. This still doesn't hit a 1% rate by CDC standards, and this points up the problem with basing funding for testing on a 1% applied to all states. This simply doesn't match the individual states' numbers and experiences.

B. Hannah presented on the VDH's program.
   a. The "Counseling Testing and Referral" model is now becoming "Testing and Linkage to Care." The "Counseling" has been dropped from the funded models. What VDH has funded has been HIV counseling – meeting people, having conversations about their risk, working and talking about what concerns them about risk/HIV/testing, and bringing them in through that process. CTR provides a forum for conversations that don't often happen anywhere else in our society, around stigmatized topics such as sex and drugs. The counseling process then helps the individual identify a goal behavior, a goal of changing behavior, and offers a range of options/ideas to investigate what would work best for the individual.
   b. This model has been based on client centeredness, but it is also a structured intervention – so that when that person gets a test, they get the face/place to continue their care. The client is followed through and barriers are removed to their process – care, other STD testing, etc. The anonymous network can offer a good way in, and then have the support of the counselor to talk about vulnerable topics and offer a direct way to get people to the next step of care.

C. TLC – Testing and Linkage to Care – is now the strong focus. In urban centers there is a larger chance of testing a LOT of people and reaching more positives. You are simply more likely to find positives based on numbers/population. There is still an emphasis that you offer high risk negatives risk counseling but BIG emphasis on testing a broad range, and getting them linked.
   a. Vermont is doing our best to hit the 1%... it is challenging. Working hard on how we can do our best to hit 1% **and** provide a service to Vermonters that isn't available any other way. There is a tremendous amount of stigma reduction that happens through CTR.
   b. As CDC reduces funding to high risk negatives, CTR becomes even more important, since it IS funded by the CDC and we can still reach high risk people.

D. Hannah discussed the 2012 and 2013 statistics.
   a. 2012: 3,080 tests; mostly Planned Parenthood; 3 positives; 0.1% positivity rate.

b. 2013: 569 tests through September; 3 positives; 0.5% positive rate.
c. Major factors in differences relate to Planned Parenthood.
    i. VDH used to fund Planned Parenthood to provide screening tests (not CTR) and their data was included in Vermont totals. This is no longer the case – VDH still supports PP around identification of positives and linkage to care, but no longer gets data from them as we are no longer funding their testing service.
    ii. VDH testing resources are now focused on the community sites that could not continue HIV testing without VDH support.
d. Based on the information over the last two years, Hannah and Daniel think that a 0.25% positivity rate would be a good potential benchmark. The obvious hope is to increase the positivity rate by reaching the highest risk populations with the testing efforts.

E. Medical testing versus CTR
    a. VDH hopes to balance encouraging medical providers to offer routine testing, with the important service the community sites can offer. The positivity rate required through medical providers is much lower (.1%), and medical testing reduces stigma, helping routine testing become the standard of care. The CTR network is specifically for people who do not have other resources or who have fears of doing testing through medical provider. Goal of focusing VDH resources on the most high need/high risk populations.
    b. Hannah working with the office of Maternal and Child Health and healthcare reform to get HIV testing part of the mainstream services for everyone with access to providers.
    c. Focused on a both/and approach – get into the medical offices and have a system that will reach people who may not have care.

F. What if we don't hit 1%?
    a. In the world of STD, traditionally "if you don't hit 3% positivity, your site is defunded." Have NOT heard that model proposed for HIV. This is the same paradigm that is now emerging in HIV testing world, however.
    b. There is a great deal of pressure on the CDC that "1% for all does not make sense."
    c. In addition, Vermont has been complimented by the National Monitoring and Evaluation Center for our work in linking people to care.

III. VERMONT'S INNOVATIVE HIV TESTING PROJECTS

A. **Mike, RU12?:** New program, 6 degrees. Working with the CCC. The model is social network testing, focusing on who is in your social circle. Runs in concert with RU12's MPowerment program – GLAM. With these services in place that serve MSM and that MSM access, incorporating this testing model has been very effective in promoting other testing strategies as well. MPowerment and 6 degrees works very well together.
    a. Expanded drop in testing times to reach people with barriers to accessing those times.
    b. Getting connected with community care advocates, defined as people who are positive or high risk negatives and are connected to other peers who are at high risk for HIV.
    c. Specifically looking for people to be care advocates in communities of men using substances in conjunction with having sex.
    d. Recruit community advocates, train them and talk to them about how to connect with their peers. They go out and facilitate a CTR session. It can be at the center, or we can go to them (HIV testing party or CTR "house call").
    e. These advocates are compensated for each CTR session they facilitate.
    f. Stayed pretty loyal to SNT model as written, and then connected to others implementing this model. Struggled with potential community advocates – people who did not realize that they WERE connected to others at high risk. Others who wanted to help but didn't know HOW to connect with higher risk folks. Had to find a balance of trying to find the best community advocates to reach folks. Found the best way to determine if the person was right for being an advocate was to "interview and assess" people on the spot, get them oriented and trained instantly/immediately. Program then became MUCH more successful! "If we waited until we had three people interested before we trained them all, we would have waited forever."
    g. Compensation: Bumps between program design and implementation. Each CA financially compensated, but barrier we ran into was we were only able to give gift cards, and that was

definitely less appealing to some CAs. We found it helpful to highlight the professional development aspect to the CAs. Tried hard to pay attention to what gets people more excited.

h. Outreach testing getting the most response –testing OUTSIDE the community center.
i. Have hired a dynamic new coordinator – already connecting us all over the place!

B. ***CONVERSATION RE: SAFETY OF FIELD TESTER:*** Jo asked about changes to policies that are allowing for outreach testing, given past restrictions based on concerns for safety of the tester in remote testing. Hannah explained that at that time, there were no protocols for outreach testing, and that this new ITP (Innovative Testing Program) has brought in a whole new set of considerations that are moving the VDH in the direction of protocols that have not been advocated in the past. Protocols are underworks now, and the sites implementing the ITPs that involve field testing – have had to produce a plan and have it vetted by the VDH office. As processes are solidified, the option of ITP models will be available for other organizations.

C. Peter, VT CARES: CVCT – Couple Voluntary Counseling and Testing, or "Testing Together." Point of the program is to test the couples at the same time, and allows couples to come in for 45 minutes. It is less about past risk, and more about talking proactively about the future and the ways the couple will make decisions together to keep each other safe.

a. Gay male/bisexual couples and other relationship configurations.
b. Builds off the support those relationships have.
c. Allows the men to talk to each other with a "referee" in the room to keep the conversation grounded and moving forward.
d. Attempts to build a plan that the couple is agreeing to.
e. Guys really like it once they come in, but trouble recruiting. Giving gift certificates to restaurants.

D. **Roy, PWA Coalition:** Adapting a model used with heterosexuals in Africa – testing people together. Grew out of finding that 50% of new infections were from a primary sexual partner.

a. Interesting to see couples come in who believe they have agreements and that both are on the same page, only to find out that they had different concepts of the "agreement".
b. Down side is recruiting people to come in.
c. When ask "why aren't you doing it?" we are finding that there are some specific issues people have, about keeping CTR an individual process.

E. **Sue, APSV:** Social Network Testing, based on bringing in recruiters who will talk to their social connections about coming in for testing.

a. Recruiting through CTR – if an individual describes a high risk factor, they are asked if they would like to be a Care Advocate.
b. Also do outreach in community and presentations at Methadone Clinic to reach IDU.
c. Targeted populations are high risk MSM and high risk IDU.
d. Some of APSV clients have become Care Advocates.
e. Having advocates get people to come in to the Project to get tested has proved a barrier. The increasing possibilities of now going out into the community are opening things up, for instance the testing party concept.
f. Incentives of gift cards, gas cards, Price Chopper cards. Advocates get $10, then an additional $10 for every person they bring in to test. The person testing also gets $10.

F. **Laura, H2RC**: Conducting targeted testing with IDU and MSM communities.

a. Reaching out to IDU through the syringe exchange.
b. Struggling with the incentive, concern that people may be coming only for incentives.
c. A number of those testing have tested positive for Hepatitis C.
d. Hard to establish contacts with MSM community, not sure how persuasive/pushy to be.
e. Pursued venue testing with MSM, at Faerie Camp Destiny. Great experience, the Faeries have been very welcoming and supportive. Encouraging guys to test. Have been able to network well through this group. They love having the testing available on site.
f. Currently trying to work with a group of young men who are living with HIV, and this has been harder. Harder to get the men to open up and talk.

G. **Deb & Zapora, CCC:** gettestedvermont.com, program of Fletcher Allen. Website providing testing info, sites, easy resources, clear explanations.

a. Advertising on Manhunt has been very successful.
b. Thinking of adding HepC testing info. Already tied into STD testing network/resources.
c. When the CTR information comes back with answers to "where have you heard about testing," gettestedvermont.com comes up.
d. Tied the site into the DOH 11years.org site.
e. No longer funded, but keeping up the bare minimum–up to date and active.

IV. QUESTIONS FROM THE COMMUNITY?

A. Community asked a variety of questions
   a. In couples testing, do you gather risk criteria with both present? Pre-survey they take; pre-survey is used to weed out the possibility of coercion – at any time, any member can switch to an individual test immediately.
   b. What happens when someone doesn't meet the criteria of the ITP? They may get the incentive for coming in, but if they don't meet the criteria, they don't get counted toward the CDC's ITP numerical goal.
   c. How many are not meeting the standard? Hard in Vermont to calculate stats right now with such small numbers and newness of the ITPs this year.
   d. What are the CDC number goals? All ITPs have a goal of meeting 100 tests
   e. What about home testing? CCC has seen two patients who did home testing and discovered status. Immediate confirmation test. What we hear from Drew (Andrew Thomits, OraSure Representative) is that OraSure has counselors who have a lot of training experience on the hotline number for the home test. The kit also connects people to the National Prevention Information Network.
   f. Do we know who is doing home testing? What we might need to do to target them? This is a whole new arena and we don't have a lot of information.
   g. Is there the potential for an ITP about getting home tests to people who won't go near a testing site? Giving out free tests with numbers to contact in Vermont? The ITP field is opening up and there will be more opportunity to suggest new ITPs.
B. Given that segue, conversation moved on to Future Ideas/Needs.

V. FUTURE IDEAS/ NEEDS

A. Between May and June of 2014 VDH has to release a new call for proposals, and the department is constantly reassessing what makes sense to ask for from applicants, and where we can go within CDC guidelines. WILL be looking at ITP version 2.0.
B. There is certainly a possibility for a suggestion to arise for an ITP with a home testing component.
C. Conversation on which modality helps connect people to treatment the best.
   a. All are great, Vermont has a great track record of linkage.
   b. The CCC is in fantastic partnerships throughout the state with testing sites. Zapora comes down to the sites when a positive is being delivered
   c. In VT, the vast majority of our positives have been linked to CCC that same day.
D. For more publicity and recruitment, Chris will put the ITP information into the PWA newsletter.
E. **NEED:** There is a dearth of close medical care for people in numerous areas in the state. Limited number of HIV doctors away from the population centers. Pharmacies are a problem as well – lack of pharmacies, lack of pharmacy choices.
F. **NEED:** Knowledge from recent HIV conference in Concord, NH, *in communities where there is a strong HIV medical presence the number of people lost to care is far lower.*
G. **NEED:** Route 100 corridor does not have a lot of medical services connected to it and transportation is very hard/expensive. Distance of care is a huge problem and linkage suffers when there is no convenient option for care. Burden ends up on the ASOs to transport people.
H. **Is there a NEED around CTR services?** Is there a gap present? Concern about access for women, as it is not often offered to women. **NEED**: recommended at all hospitals and medical centers.
I. Commissioner has signed on to annual testing recommendations. **NEED** is to get into the medical locations and make the CDC recommendation get in place as standard policy. When someone goes to emergency, make it standard policy to capture them in that moment. Train people.
J. **NEED:** Better education, checks on curriculum. Health teacher repeating misinformation.

K. **NEED:** Parity for reimbursement. Address the disincentive to testing low risk people through the funding mechanism. Community centers get paid less for a low risk test than for a high risk test. **THIS NEED HAS BEEN MET**. Parity of reimbursement is being put into place.
L. Clear from discussion that no one practicing community testing ever turns away someone for being "low risk" but in effect, CDC pressure on testing policies are advancing this concept.
M. **NEED:** Recognition that primary risk factors may manifest differently for women. Two of three female positives did not meet the "high risk" criteria. "Primary partner risk" often looks different for women.
N. **Are the resources there for widespread medical testing? NEEDS:**
    a. Raising provider awareness – grant to do provider education.
    b. AIDS Education & Training Centers have done trainings with providers.
    c. General outreach campaigns.
    d. Issuing health advisory to the medical network – disseminate info to providers.
O. Under health care reform, testing is part of the prevention continuum and covered for free.
P. **NEED**: Getting the word out further about the community sites?
Q. **NEED**: Mobile testing van? Peter – VT Cares partnered with College of Medicine on research on a mobile testing van; intrigued by the possibility; second year students are investigating the most rural places to see if other providers see it as feasible and how it might be structured.
R. **NEED**: Improving services at Community Health Centers to improve offering of testing and linkage to care. Lack of funding for CHCs.
S. Dr. Sarah Mooney is going into Community Health Centers and private practices and talking about HIV, HIV testing, HIV care – MORE than happy to do so, **if you know of a doc's office that will have Dr. Mooney come, please let Deb K. at CCC know**. VDH is happy to play a role in this.
T. **NEED:** More of that (letter S). More training for providers.

- ***BUSINESS MEETING – CAG HOUSE KEEPING***

VI. PREVIOUS MINUTES:

A. Please paginate minutes
B. Agencies – Twin States and CCC were both represented at the last meeting.
C. Chris – should be listed as Co-Chair of PWA Coalition, not co-facilitator.
D. Chuck made a motion to accept the minutes as amended. Deb seconded.
E. No discussion.
F. The minutes were accepted unanimously.

VII. PUBLIC COMMENT:

A. Peter – VT CARES is doing some clinical trials for HIV/Syphilis tests.
B. Dan – Raised concern about how to add a medication to the HIV/AIDS formulary. The concern is that AMAPs have been reluctant to add weight loss meds as these can be seen as cosmetic; there is a lot of resistance to accepting the medications to the formulary. In HIV, weight loss meds are used for reduction of lipodystrophy, medical treatment for a side effect of a disease, not cosmetic. Dan would like to advocate for another drug to be added.
    a) Process of medications and formulary was discussed.
    b) VDH cannot take a role.
    c) The CAG as a group can make a recommendation that a medication be considered.
    d) It would go before the HIV Formulary Committee and the two doctors who run the committee. Ultimately it goes on to the Commissioner if the Committee chooses to consider it.
    e) Question arose about the link between the Medicare formulary and the VMAP formulary. If it is not on Medicare formulary can it even go on VMAP formulary. This needs to be ascertained first.
    f) Concern raised that many CAG members do not have medical knowledge and are not in a position to make this kind of a medical recommendation or advise on a particular drug.
    g) **Next Steps:** First find out if VMAP can cover it. If yes, then CAG can take up the question of considering a motion asking that the formulary consider it, or a letter from CAG asking for that consideration. Varying opinions and concerns were expressed, as follows:

i. *This is a consumer concern, and as such CAG can/should legitimately be involved in making recommendations that the medication be considered.*
ii. *Would feel uncomfortable making a medical recommendation with any kind of medical background. Do not know anything about other aspects of the drug.*
iii. *Very bad side effect, very debilitating, NOT cosmetic.*
iv. *Affects a lot of consumers.*
v. *Would like more information about the drug before any motion/letter.*
vi. *Verbiage on medical impact of lipodystrophy is important for any action and will be sought.*
vii. *Would like to know the cost of the drug.*
viii. *CAG needs to be careful about advising on a particular drug, not a medical body.*
ix. *Anyone at any time can write a letter to the Committee.*
x. *Providers and prescribers can write letters and ask for consideration. Consumer can write letter and include provider/prescriber's opinions and information.*

h) CAG will discuss this further if the possibility of addition exists.

VIII. ANNOUNCEMENTS:

A. Daniel acknowledged that this is Susan's last CAG meeting, and CAG is losing an amazing resource, who has been a great addition to this group. Thank you for your service as part of this group and as part of this state's HIV/AIDS work.
B. There will be a WILLOW cycle in October. The PWA Coalition would love to share info with female clients – please put the word out.
C. Twin States is looking for a male peer (het/bi). Previous male peer was wonderful but can no longer fill the role. Have a number of men who would prefer to receive support from a man, most of whom are heterosexual.
D. Roy: Drag benefit at Charlie-o's; Oct 19 benefit for PWA Coalition.
E. Visit the new PWA website!
F. Chris discussed candle sales for the holiday that will be a fundraiser for the Coalition. He will bring info to next meeting.

IX. VDH UPDATE:

A. Received very sudden notice of VMAP application due in less than 30 days that Erin is working on, preventing her from attending today. HRSA was also a 30 day deadline.
B. We have 7 confirmed HIV positive tests for the year. We know we will have fluctuations, but that is higher than normal. All seven have been CONFIRMED as linked to care. Of the five that VDH worked with, all got into care within three days of the test. This is a strong reminder that HIV infection is happening in VT and we need to be proactive.
C. Chlamydia and gonorrhea are both down, and syphilis is back to low numbers (2 this year).
D. Six acute viral Hep C infections this year so far.
E. VDH staffing – closed on Epidemiology position, ten candidates, three are being interviewed; all three have lots to offer. Viral Hep C position will be closing Thursday. With 28 applications the department has four to interview.
F. Comprehensive Plan is due every three years. When we signed off on 10/2012 we said it would be a living plan. We are adding all of this community feedback to our compiling of information for the next comprehensive plan.
G. CAG Membership committee: email discussion about people coming/not coming? Talk about who is here, who isn't here, and check in with them personally to see if there is anything we can do to encourage them to attend.

X. HOW IS THE NEW FORMAT?

Great! Wonderful! Still a little long; start to shut down around 2pm. Really appreciated. Feels much more productive and interactive. Thanks!