CAG Meeting Minutes
October 29, 11:00-3:00pm
White River Junction, VT

Facilitator: Daniel Daltry

Attending: Karen Peterson, Daniel Chase, Laura Byrne, Chuck Kletecka, Paul Redden Sr., Paul Redden Jr., Jason Redden – guest, Peter Jacobsen, Grace Keller, Jonathan Heins, Miriam Cruz

On Phone: Kim Fountain, Deborah Kutzko

Organizations/Populations Represented: PWA Coalition, RU12, CCC, APSV, VT Cares, HR2C, Howard Center
Native American Community, PWA Community, IDU Community, Younger People Community

VDH: Daniel Daltry, Chief; Alex Goode, HIV Surveillance

CHL: Alex Potter, Notetaker

The meeting was called to order at 11:05am.

I. Introductions
Daniel introduced Alex Goode, the new DOH employee in the HIV Surveillance position, coming to us with a MS in Epidemiology from the London School of Hygiene and Tropical Medicine. Kate Marsi will be starting on the coming Monday, in the Viral Hepatitis Coordinator position, as a direct services specialist. She will be taking on Alison Newman's duties, and be the disease intervention specialist. Kate comes to the DOH with an Master's degree in Social Work, and a history of working in Tanzania in the HIV/AIDS field, empowering women in sexual skill negotiation.

Daniel mentioned that Erin is not in attendance today due to changing deadlines and her work gaining access to health information on the level of a Navigator for insurance, which involves taking eight courses. She, nor Mary, will not be an official navigator for all populations for the Health Care Exchange, but she will be able to help the HIV positive community with navigating the new health care system.

VDH Success Story
Daniel then shared a recent experience indicating the importance of the integration of services we have been working toward. An individual had a reportable sexually transmitted infection and in the midst of that process it was identified that the individual was HIV positive and had not been in care for a period of time for a variety of reasons. Being in care for the STI helped to bring this individual into HIV care services.

II. Community Feedback
Theme: "Policy & HIV Care, Prevention, and Surveillance"

A. This meeting the community feedback portion focused on the VDH's written plan section on *HIV Policy Initiatives, Section D*.

1. *Goal 1: "HIV Surveillance data is available to monitor the Garner HIV Treatment Cascade from a Vermont perspective."* Improving surveillance – the VDH is trying to improve the systems in place. There is a lot of buzz around the Garner Cascade that is now referred to as the Continuum of Care. Ideally VDH wants to create our own version of the Continuum of Care, to get a solid sense of our own numbers and see where the gaps in

the continuum are happening, and where the health indicators are for those in care. Ideally VDH would like to go beyond Garner to other data sets, specifically, if individuals who have a detectable viral load, looking at the possibilities of why. Has there been a history of STIs, are they managing a Hepatitis C infection, have they interfaced with HIV prevention services – try to get a story of why there is a detectable viral load. Determine if there are indicators we are missing, look at the data as a whole, and see where our prevention and care services could be better aligned. How do we improve systems and get better data.

2. *Goal 2: "State funds will be secured to sustain HIV prevention programming that is no longer permissible through federal resources."* Examine prevention programming and identify gaps and services that aren't being covered. Historically Vermont has done this well by allocating 100k to the needle exchanges.

3. *Goal 3: "Vermont Statute 18 V.S.A. § 1001 regarding VDH data will be modified to allow online access to CDC reporting tools."* VDH would like CAG to have a conversation about this, take the temperature in the room, and determine if there are amendments that could or should be made.

4. *Additional Goal:* In addition to these items stated in the plan, another important priority is ensuring consumers have good access to health care through the health exchange. A goal is to keep track of all updates and adjustments to state health policy, to make sure VDH programming is in alignment with the health exchange.

B. Vermont CARES Policy Work: Peter reported on Vermont CARES process around becoming more involved in policy. CARES sat down as a group – with clients, staff, stakeholders – and worked to align the agency's Strategic Plan goals to match specific policy goals. Peter distributed the results in Vermont CARES Strategic Plan and a chart mapping plan goals to policy goals.

Vermont CARES – Mapping Strategic Plan Goals to Policy Goals:

CARES SP GOAL #1: Reduce the number of new HIV infections in Vermont and the health and social impacts of HIV infection.

Policy Goals

1. Support policy to make testing more accessible.
2. Support policy enhancing comprehensive sex education.
3. Support policy enhancing STI screening.
4. Support policy reducing barriers to syringe exchange.
5. Support human rights, including health care reform, economy justice, immigration reform, and civil rights.

CARES SP GOAL #2: Be a leading model of care for HIV positive people receiving care and support service.

Policy Goals

1. Support and explain health care exchanges.
2. Support policy to strengthen HIV care, medication access, rapid diagnosis, screening and support.
3. Support policy to bolster housing, food access, and emergency assistance statewide.

CARES SP GOAL #3: Be a leading voice on HIV/AIDS.

Policy Goals

1. Oppose HIV criminalization laws.
2. Support procedures that reduce HIV stigma in all levels of government and community life.

C. Peter explained that Vermont CARES will try to get involved in as many of these as is reasonable given time constraints. All of them tie together, and some CARES will focus on city-by-city, and some more directly in Montpelier. For example, the syringe exchange in Rutland is an example of localized policy CARES is working on.

D. At the end of this meeting, the HIV Providers Group will meet. CARES would like allies in this process, and hopes that the providers group will work together to have a clear plan of action to talk to lawmakers on February 7, HIV Awareness Day.

E. General discussion was held. Chuck inquired if when it comes time to look at advocating funding levels at the state level, if the group will have input into what we are pursuing. The response was yes, that this has always been the case in the past and planned for the future. Paul Jr. noted that he was particularly pleased to see Policy Goal 3 under Strategic Goal 2 – as this is an important aspect that needs a lot of support. Jonathan applauded Peter and CARES for getting this organized and outlined on paper, and asked what would CARES like to see from the consumers and this body in support. Peter answered that they would love help – as many people at the February 7 legislative day as possible to talk to lawmakers, opposing or encouraging the laws that are aligned with these goals.

F. This process that CARES has gone through speaks strongly to how VDH/CAG can adjust our state plan to make it clearer and more streamlined. Alex will be utilizing these documents in working on the plan.

G. Daniel reviewed where the VDH goals align with the Policy Goals as outlined by the CARES chart, including increase access to testing, enhance STI testing, support health exchange assistance to consumers, and securing state funding to support initiatives that cannot be supported by federal monies (e.g. syringe exchanges).

H. There is at least $60,000 in funding available for next year for Innovative Testing Projects as well as testing reimbursement funding. Organizations can be testing locations regardless of funding from VDH. A structured format is being introduced to ask new VMAP sign-ups if they have partners who may need care or testing.

I. The question then turned to if there were policies that need to be focused on that have not been covered in the materials presented thus far? Are there other goals that need to be written into the plan? Consumers would like to think about this and provide additional feedback to VDH.

J. The topic then turned to an in-depth look at Statute 18 V.S.A. § 1001.

- ***Statute 18***

1. Suggested amendment to Statute 18 that requires the VDH to maintain names based related data on a non-networked computer.
    a. Daniel reviewed the difficulties with the statute. We have had the non-networked system since 2008, and therefore have been offline since 2008. But this is now creating limitations that are causing a lot of problems with the federal reporting systems.
    b. Example: When filling out STI data on syphilis, the CDC has a field asking "how many of the syphilis cases were tested for HIV". With the current system, VDH must fill in "Refused" to this field, which makes it look to the CDC as if we are not following the CDC rules.
    c. This is creating problems only for the VDH. ASOs are all online and networked with CareWare.

d. Daniel described a standard reporting process that should have taken two hours, but took four days, an outside consultant, and the reporting still was not successful. This is just one example of many.
e. VDH has worked hard to negotiate with the CDC and find other ways to share Vermont's data. The CDC has stated unequivocally that the data must be in their system.

2. Extensive discussion ensued.
   a. Concerns were expressed concerning the original intent of the statute, which was to ensure that no consumer's information is shared with a provider in another state without that consumer's knowledge.
   b. The protections in place were reviewed. All data is shared only on an aggregate level, not on an individual level. The data is encrypted, extensive firewalls are built into the VDH systems, and the only place the information goes is to the CDC and HRSA. A comparative system is that VDH exports STI data on a weekly basis, and has since 1998, and there have been no breaches in the VDH or any operating system in the country with the system.
   c. The National Electronic Data Services, which is the system that VDH could be using, is an excellent system that is very specific about who can even see the aggregate data, with individual user sign-ins. Not being able to use the NEDS compromises our access to good data as well.
   d. A similar issue came about when names-based reporting was put into place initially. Ultimately, if Vermont wanted CDC funding it needed to move to names-based reporting.
   e. Deb Kutzko noted that this will affect the Ryan White funding in the future. The Garner Cascade is how we will be judged in the future and some of that data comes from CareWare. Without the data from the beginning stages of the cascade, we can't follow the rest of it accurately. Deb stated that she trusts the systems to work.
   f. Dan raised the issue that while we are trying to afford extra protection because of stigma related to HIV, we are also trying to fight stigma, and get rid of it. This type of protection can be seen as part of that stigma. He agreed that the situation should be changed to allow for better reporting, particularly if it affects Vermont's ability to receive funding.
   g. Chuck mentioned that since changing legislation is what the policy group does, maybe this issue should go to that group.
   h. Daniel mentioned that Vermont stands a chance to be recognized nationally for our system of getting people in care, if we can report the data. That will command attention around the nation and will help replicate our good work.
   i. Peter noted that contextually, the statute was written during a time this was more contentious and there was less understanding of the technology. Things have changed and this feels less terrifying now.
   j. It was pointed out that it would make more sense for there to be an equitable system, and that the VDH and ASOs be held to the same standard.
   k. Jonathan stated that it would make sense for there to be a motion to "make the statute suitable to what is needed to report data to CDC and HRSA more efficiently." There was agreement from the body to proceed in this manner.
   l. Jonathan noted that he agrees with this approach and wants VDH to be able to effectively use data, that his main concern is that there be <u>transparency to clients</u>, and that it be explained to those whose data is being reported what is happening with it and how it is being handled.
   m. Daniel reported that yes, that caveat (client notification) is there, in this law, and would not be changed.
   n. There was unanimous approval from the body for the motion that the **"statute be modified to reflect what the VDH needs in order to be able to effectively report and**

use CDC data."

o. Daniel would like to fashion something, bring it back, show it to the body, and then give it to the policy group to march it forward if approved. It was agreed that this is how we will proceed.

III. CAG Housekeeping

A. Meeting Schedule: It was determined that the November CAG meeting cannot take place. It was voted that we will not try to reschedule for later in November or December due to the holiday season, and simply move on to our January meeting. At the January meeting we will have the dates for the forthcoming meetings in 2014.

B. RFP: The goal for the RFP is for the VDH to have it in place by the end of May, so applicants can have two full months to be working on it.

C. Minutes: Change noted – ASPV is APSV. ☺ Chuck moved the minutes and Karen seconded, and the minutes were unanimously approved.

D. Public Comment: None.

E. Announcements:

1. Vermont CARES finished the clinical trials for HIV tests and syphilis tests – found more syphilis cases, and will definitely do more clinical trials in the future. It was very successful.
2. Vermont CARES is advancing the basic research into mobile HIV testing. The College of Medicine is doing a lot of legwork on the sites.
3. The Rutland exchange has been very busy, and the Rutland area remains a big priority. The initial goal was reaching 20 people total and they have been reaching an average of 20 people per day. They have also done 16 Hepatitis C tests.
4. Daniel noted that all the syringe exchanges run in the red and there is not enough funds to assist. With Hepatitis C testing, we are finding a 30% positivity rate, and we know there is often co-infection. Laura reported that she is applying to the AIDS United syringe access fund, a national grant source. Jonathan suggested that if there is no funding specifically for Hepatitis C testing that agencies might apply for grants for transportation to do educational seminars for incarcerated people and treatment centers to discuss Hepatitis C one-on-one. Daniel noted that this is an idea worth investigating. Now, with the Hepatitis Coordinator position filled, the VDH will be working to get this person out to do presentations. Jonathan Radigan went to the NASTAD hepatitis conference given the viral hepatitis coordinator was not in position; Jonathan presented that we do targeted education. One hope is it will not be only education, but direct service too.
5. Karen reported that both APSV Case Managers will be going to Community Assistance Providers training for the healthcare exchange. They will not be certified navigators, but the next level of assisters. In order to get this training, they will be serving anyone in the community, not just our clients.
6. Chuck reported that they had six Willow participants. The PWA Coalition is trying to host a World AIDS Day program on Sunday, December 1. Miriam commented that Willow is great, and she would encourage women to attend.
7. Laura announced that H2RC will be doing Healthy Relationships the first weekend in December. If anyone knows MSM who might be interested, please refer them and put them in contact with her.

F. VDH Announcements:

1. Jonathan Radigan was very inspired by the models at the viral hepatitis conference. He will be transitioning what he learned to the new hepatitis position at VDH. One big piece of news was two new medications that are having amazing clearance rates.
2. With the new coordinator we want to broker partnerships we can have, become a part of the Blueprint for Health services. Hepatitis C needs to be a part of that conversation, and we need to talk to what we can provide to them and the inroads we can make with public health expertise. Partnerships with internal and external entities that VDH has will be highlighted in the new positions.
3. Daniel will be going to NASTAD in November.
4. Despite the fact that it has now resumed, the federal government shutdown will be having unknown ongoing effects on how much and when the CDC will be providing feedback on our STD application.

G. What would people like to see in the new year?
    1. Jonathan would like to get a grant in for Hepatitis C training and transportation.
    2. As a consumer advocate, he would also like to see that every ASO have, for their clients, a client handbook with detailed information about their services and whatever their grievance procedure may be. Daniel noted that HRSA is now mandating a grievance procedure for agencies.
    3. Chuck asked about the state allocation and how far it goes, and Daniel reported that it is a two-year cycle. Chuck said he would like to see us push for more funding for IDU syringe exchanges and Hepatitis C education.
    4. The state of the Innovative Testing Projects were inquired about. Daniel answered that those are what the VDH will be putting out RFPs for in the next funding cycle. Up to 10% of the funds can go to Hepatitis C.

H. No further comments, and the meeting was closed.

Respectfully submitted,
Alexander B. Potter