Vermont HIV/AIDS Community Advisory Group Meeting Minutes
September 23, 2014; Wilder Center, Wilder Vermont

Attending: Roy Belcher, PWA Coalition; Laura Byrne, H2RC; Dan Chase; Jonathan Heins, PWA Coalition; Grace Keller, Howard Center; Chuck Kletecka, PWA Coalition; Karen Peterson, APSV; Paul Redden III
Vermont Department of Health: Daniel Daltry; Erin LaRose
Center for Health & Learning: Alexander B. Potter

I. VDH UPDATES

A. CDC Visit Review

1. Daniel reported the CDC visitors were very impressed with CAG. Impressed with the rich and robust discussion about a topic that has been controversial (PrEP). Noted that people obviously felt comfortable sharing their honest thoughts and feelings. Liked to see spectrum of participation.
2. Daniel described CDC visit – they traveled outside of Burlington to display the full spectrum of the state. Did a site visit in Chittenden County with Pride Center of Vermont, demonstrating the need for prevention with high risk negatives. Under the current funding there would be no funding for high risk negatives for Vermont. They saw the need for our programming. We were able to highlight other programs (CLEAR and CRCs) doing work with high risk negatives that don't necessarily reflect CDC's priorities. Then traveled to H2RC to show off their work and the syringe exchange. CDC was "beyond dazzled" by the Good Neighbor Clinic syringe exchange. VDH wanted the CDC's visit to be representative of the work that is being done in VT, and is needed here, even if there is not currently funding available for it.
3. Regarding CDC and available funding, Laura reported that she applied for H2RC to receive funding from the CDC's "direct community based funding" RFP. She applied for a high impact community based testing intervention, based on replicating her Faerie Camp model nationwide. The proposal was turned down with the statement that programs "must be in your state's metro area." Daniel noted that the minimum award for this funding was $355,000 but only a small nexus of players were truly eligible, and 30 awards were made.
4. Daniel invited comment on the CDC visit.
    a) Karen – didn't get to talk to them much so no specific comments on visit
    b) Daniel C – they didn't say much but backed up their statements
    c) Laura – they were very accessible in their visit; asked if we distributed condoms too, and we commented that absolutely, "we distribute so many so often that we forget to even SAY anything about it!" I just seems like such a given in their programming.
    d) Daniel reported that CDC wants to know how many condoms are going to positive clients, and we've been reporting that we "don't track who takes the condoms, as everyone should have condoms, and condom distribution is embedded in all programming."
    e) Jonathan inquired if it would be okay to send condoms to a state that was having difficulty getting them (eg Minnesota) if they were not being used. He reviews the condom supply before every Retreat and removes A LOT of expired ones every year and would like to see them go where they may be better used. Daniel said that they could be sent, but possibly check with other regions of Vermont first.
    f) Daniel reported that in meeting directly with the CDC representatives for this area, it is clear we do have leadership that understands the problems/needs in the rural areas and it's not just lip-service. Stacy

(from CDC) noted that it is Vermont's decision what they apply for/choose for interventions, but must be very clear about how funding request impacts low incidence rural areas. She stated the leadership is always asking for verification if programming matches the needs of the low incidence rural areas.

B. PrEP Follow Up:

1. Daniel discussed the Vermont Department of Health website plans for information on PrEP. There will be basic information on what it is, and a series of check boxes to review "is PrEP right for me?" There will be advocacy points on how to talk to your doctor about PrEP. This will not be VDH taking a direct statewide position on PrEP, but it is VDH playing a role in dissemination of information. Daniel believes it is a fair and neutral presentation of the information. Daniel shared an anecdote of a 67 year old man, now widowed, who is not currently sexually active with men but has an interest in becoming so, and was inquiring about PrEP, which may be a situation that doesn't make the most sense for a PrEP prescription. This information will hopefully help people sort out what does and doesn't make sense for their own lives.
    a) Chuck commented that this illustrates his concern of the issue of anyone making judgment calls for OTHER people on whether or not PrEP is an option that is right for them.
    b) Daniel agreed that everyone should get all the information and discuss it, but the hope is that a good conversation will happen with people about what are the true risks this person is facing, in comparison to taking on a PrEP regimen. The VDH wants to ensure that there is regular care for at least a year while PrEP is being prescribed. Following the CAG meeting discussing PrEP, Price Center of Vermont held a community forum about PrEP which was well attended, and has prompted continuing community discussion about PrEP. Daniel reported he has had more requests for information about PREP from individuals testing positive for STIs in general. There is definitely more interest and more information getting out into the community about PrEP, and the goal for VDH is to take a role in disseminating that information without taking a position on the use of PrEP.
    c) Chuck posed the question of whether being neutral is truly a good strategy? If PrEP works as has been reported, shouldn't we promote it. If we promote PrEP as protection and it gets people into the system of care, we will likely have better ongoing contact with that individual if there are problems. Daniel agreed that this is a benefit to the continued care after a PrEP prescription – that in the event that PrEP were to fail, the affected individual would already be linked to care.
    d) Daniel noted that what Chuck raised is an excellent topic for discussion and that it is an issue for the CAG to think about. VDH looks to CAG for guidance, and if CAG wants to take a strong stand on PrEP, that will be considered. Sometimes the VDH also will act on its own, in that the commissioner could unequivocally approve an endorsement of any given treatment/prevention option.

C. CTR Updates

1. Testing technology – VDH is looking at the issue of "are we using the best test?" Current mode of testing is the oral swab, but is this the most appropriate or should we be doing a finger stick?
    a. Tried finger stick pilot at syringe exchange but was not continued

b. There has been improvement with finger stick in early detection and predictive positives.
c. Hannah will provide information to testing network statewide and VDH will continue to monitor latest technological advances. New test not yet FDA-approved that is testing for HIV 1 & 2. We were able to say in our CDC visit that we were already researching it.
d. Continue to examine new and different testing platforms as well.
e. Karen asked about information on home tests. Daniel reported that currently they have no surveillance on home test usage geographically, and he will check to see if it is available. Orasure is saying the home test is not taking off as they anticipated. Not sure why. Laura suggested cost is too high - $40. People are resistant to getting tested anyway, and probably don't want to buy a $40 test. Jonathan mentioned that people frequently test not to check if they have HIV or not for themselves, but to "prove to someone that they don't." Therefore validity/credibility of home test may be in question for some folks.
f. Hannah is looking at doing a refresher series for testers – every quarter doing refresher webinars for all testers based on needs arising and to supplement tester services. Trying to give people what they want – first presentation will be on testing technology. Grace asked if they would be required and Daniel said they would ask folks to do at least two per year. Hope is that these will be beneficial and people will want to attend.
g. There are 8 new certified testers in Vermont.
h. There is a new HASH designee in the Springfield area. Six public health nurses around the state bill 3/week to the HASH program. Has historically emphasized testing services. Springfield is a catchment with a lack of services. Prevention activities are needed

D. Syringe Exchange Updates

1. Grace and Laura reported on a meeting with Acting Commissioner of Health Tracy Dolan about syringe exchanges. People in attendance were Tracy, Laura, Grace, Daniel, Peter Jacobsen, Tom Bolton and Virginia Renfrew.
2. Tracy was supportive but it was very clear that there is no money available to support it. She was very encouraging and said she would support Vermont organizations talking to the national senators to work to get the ban on federal funds lifted, which would be a huge help. That is not looking hopeful either.
3. Definitely felt heard, but not expecting much change to come of the meeting. Best news was that Tracy was very open to the idea and discussing it.
4. The allocation has been flat at $100,000 while the number of needles exchanged is increasing a lot. Grace is currently being forced to limit people to 100/day.
5. Daniel reported that there will be a new New England Caucus on Opiates, and Peter Shumlin is the chair. It would be excellent if Peter could take to that caucus the message that it is time to collectively say "lift the ban."
6. Daniel reported that New York moved quickly on an ACA caveat on high impact prevention services, and created a targeted prevention case management program. Outlined how costs would be averted from hospitals and what these programs could mean for treatment.
7. Tracy D. asked for a summary on NY's project, with an outline on how they are billing it. She is very willing to present it to Medicaid. This is an opportunity to talk about targeted case management overall. Maine has also instituted a targeted case management program.

8. This may be a domain to strongly pursue for medical case management, where Medicaid would be paying/reimbursing for services. Pathways to Housing is billing Medicaid for case management services
9. Syringe exchanges have had a [Hepatitis C?] positivity rate from a low of 20% to as high as 60% among Vermont testers. We see a clear link that if we can find this population and get them into Hepatitis C testing and get them into care that will hopefully clear their infection and control the spread of HCV in a tight community.
10. Grace reported Elton John Foundation has stopped funding Vermont at all due to small size. They are definitely looking for creative ways to keep this important work going.
11. Daniel identified that the meeting communicated this is the right issue at the wrong time. It has support from Tracy and Dr. Chen , but it all comes down to the operating costs – there is not only no additional money, but all AHS budgets are tight. VDH is looking at 5 to 10% cuts to budgets over the next two years.
12. Peter Jacobsen asked Daniel to report that they have been given approval for a fixed site in Rutland for an exchange, with both the mayor and police chief signing off on it. This represents a huge amount of work done in a very short period of time! This has turned around a person who once said "absolutely not" to saying "obviously this is needed."
13. Grace and Laura were asked about costs.
    a) Box of 100 syringes costs between $7 and $9, and come in cases of twenty five boxes. The cost of sharps containers also adds to expenses.
    b) The federal ban is only on syringes and staff time specifically, other safer injection supplies are covered.
    c) Paul asked if money can come from an individual to support these efforts, and it can.
14. Chuck asked how many syringes come back. Laura reported 75%; Grace reported that she could not name a specific percentage, and that they also track how many needles are found in the community. She clarified that they are not a one-for-one exchange.
15. Daniel reported that VDH is pursuing internally the possibility of being a sharps collection site. This would basically involve getting appropriate receptacles, installing sharps containers in the bathrooms. This does not replace syringe exchanges but it is at least a repository.
16. Barre, Newport and St. Albans are asking about syringe exchanges and asking what else can be done in their areas. Peter is talking to communities but it seems that interest is outpacing even his outreach! Momentum is definitely picking up all over on this issue.
17. The governor has an opiate task force, and there are PCs – prevention specialists working on the governor's opiate initiatives – who are stating they want syringe exchanges. They are tasked with looking at all drug issues as part of the prescription drug and opiate dependence initiatives. They need to submit to ADAP by October one to three action steps on which they will engage with their community. ADAP will then respond. PCs have definitely heard that syringe exchanges are effective and important.
18. In response to inquiry, Laura reported they have distributed 50,000 syringes this year, and Grace stated they have 97 members in the exchange and have definitely distributed over 100,000. Grace noted that the current 100/day cap is not something they ever wanted to have to do but they are running out.

An exchange in the Midwest donated 100,000 syringes to Vermont when we were two weeks from running out completely.

E. Federal Funding Update

1. Two days before the interim progress report on Part C funds were due, letter arrived that decisions have been made about future Part C funding but they would be announced after the progress reports were submitted.
2. VDH expects to hear within 90 days.
3. We do not have a good sense of what final award will be.

F. Surveillance Update

1. CDC is asking that all CD4 counts be reported. VT HIV surveillance report has been consistently critiqued because all CD4 counts have not been reported.
    a) There is talk of a legislative change. If it moves to this level there will be a public comment period. VDH will make information available through the group if there is a public comment period.
    b) If VDH were to report CD4s, our system would report all CD4 counts rather than CD4 counts of HIV positive individuals, so Daniel is doubtful that VDH would move forward with this. CDC language says "HIV positive CD4 counts" and it would not be possible with our system to sort the HIV positive individuals from any others. Our lab and the labs VT uses don't separate. CD4 is connected to a name identifier.
    c) Responding to inquiry about other states, Daniel reported that 40 states have CD4 and viral load reporting in place.
2. Alex at the VDH – the Surveillance Coordinator – has been running the numbers and put together an infographic. Daniel distributed it. It is an excellent example of data crunching and how it can help communicate about HIV in Vermont.
    a) 670 individual case reports on record. This is higher than previous reported.
    b) It is known that at least 70 of those people have not been able to be found as residents in the state of Vermont, and we do not know where they are. Therefore that 670 could be 600.
    c) We know 521 are in care. 90% of those in care receive it at CCCs.
    d) Daniel reviewed the other surveillance numbers on the data sheet. This collection of data and reports will help with Vermont's assessment of our performance on the care continuum.

G. Other State Updates

1. New VMAP coordinator has been hired, who is very versed in Medicaid and the systems we use on a daily basis. Previously she was working in DCF training people on Vermont Health Connect.
2. VDH is in the final stages in negotiations around housing and need some final items from some directors. Cannot state anything yet, but hope to be able to speak about this soon, and hope that it will bring some solutions to the housing needs that have been voiced.

II. Needs Assessment:

A. Alex reported on status of Needs Assessment. Early data summaries were reviewed but not distributed as data is in raw form. At this time any data should not be released further than a general discussion to share where we stand with responses and where more response is desired.

B. Alex identified the following:

1. Have had large positive response to interview requests, and therefore have expanded the number of interviews being conducted.

2. Focus Groups have not been successful. Have had to cancel for lack of sign up. Places that were hoped would be good options have not produced enough people.
3. Survey response from HIV positive people online has been very low. Some paper surveys have been turned in but still much lower than hoped.
4. Survey responses on Prevention have been excellent, and the advertising has definitely worked to pull people in for that survey.
5. Alex has two focus groups arranged, but would like more. Talk to him if you are able to help organize for a specific population.

III. CAG BUSINESS

A. Minutes

1. Section E, typo. Sentence should read: "A surveillance grant on gonorrhea is monitoring 12 states and 115 counties…"
2. Zpora's name has been misspelled. Alex will correct this going forward.
3. Jonathan made a motion to accept the minutes as amended. Chuck seconded. The vote to accept the minute as amended was unanimous.

B. Public Comment

1. Roy reported PWA Coalition is holding a WILLOW training last weekend of October – 10/30 through 11/2. Please refer people in. Have 2 so far, need 6.
2. Grace reported that it has been reported that there have been 70 cases of the Narcan spray being used to save the life of an individual who has overdosed. There were 68 overdose deaths in Vermont last year. People are asking about potential withdrawal symptoms following the use, but those reporting use have said that this is not the case – some disorientation is the side effect most commonly reported. In the ER, individuals are given a much higher dose intravenously which may cause the withdrawal symptoms.
3. Peter asked Daniel to report that VT CARES is investigating a partnership with UVM College of Medicine to ramp up PrEP referrals. They are putting out a survey to medical providers statewide to see if they are comfortable prescribing PrEP – if you have a doctor you think would be a good fit, email Peter. Both the Pride Center of Vermont and CARES will take a role in this.

C. Community Concerns/Cheers & Fears

1. Thanks to Alex for Needs Assessment work.
2. Thanks to Alexandra at VDH for data crunching/infographic.

Respectfully submitted,
Alexander B. Potter