Vermont HIV/AIDS Community Advisory Group Meeting Minutes

Tuesday, February 24, 2015

Wilder Center, Wilder, VT

Attending: Tom Aloisi, Agency of Education; Laura Byrne, H2RC; Daniel Chase; Miriam Cruz; Jonathan Heins, PWA Coalition; Peter Jacobsen, VT CARES; Grace Keller, Safe Recovery; Michelle Kiefer; Chuck Kletecka, PWA Coalition; Deborah Kutzko, CCC; Zpora Perry, CCC; Karen Peterson, APSV; Paul Redden III; Paul Redden IV.

Telephone: Kim Fountain, Pride Center of Vermont; Pat Gocklin, DHMC

Vermont Department of Health: Daniel Daltry; Erin LaRose

Center for Health and Learning: Alex Potter

Meeting was called to order at 11:18 a.m.

I. CAG BUSINESS

a. Deferring to timing difficulties, it was decided to begin discussion of CAG Business and move on to DISCUSSION ITEMS when delays were resolved, then return to any remaining Business.
b. November 2014 Minutes: Deborah moved the minutes, Karen seconded. The minutes were approved unanimously as written.
c. The date of the April CAG meeting was clarified to be Tuesday, *April 28*.
d. The discussion for the April meeting was determined to be Vermont HIV Testing operations, with the presentation of some ideas for modifying those operations.

II. DISCUSSION ITEM #1: H.98

a. Chuck Kletecka facilitated the discussion of H.98, a Vermont House bill requiring data on HIV/AIDS to be stored on networked computers.
b. Background was provided.
    i. In 2007 when CDC required names reporting of HIV/AIDS, the community put in protections, one of which was requiring the information be stored on a non-networked computer.
    ii. In October 2013 CAG agreed to change the networked computer restriction due to severe difficulties it was creating with reporting data to the CDC.
    iii. There were other protections that were proposed to be changed in the bill that were not discussed at the October 2013 meeting.
c. Current status.
    i. Chuck has spoken to the House committee members to say community was not consulted and the committee heard that and opened discussion.
    ii. Met with David Englander, a lawyer: Dr. Chen (Harry Chen, MD, Commissioner of Health) and Englander went into discussion with philosophy of treating HIV as any other illness as a method of reducing stigma.
    iii. Chuck expressed appreciation of the position but countered with concerns about real world stigma that is not simply disappearing and raised the issue that anything that removes protection of identity in a small rural state potentially discourages people from getting tested and getting into treatment.
d. CAG considerations for this meeting.

i. Items from Chuck's testimony on February 18 was provided as a handout, and Chuck reviewed the specific places in the bill where there was agreement and disagreement, and CAG discussed.
ii. The "cell suppression rules" were reviewed, that small cells of less than 5 people cannot be reported by number. This is operational across all VDH reportable diseases.
iii. **Point of Disagreement with Bill**: #5 [Subdivision (c) (p6, line 14 – 19) concerning re-disclosure of information] was discussed and CAG confirmed that it *approved* of keeping the strikethrough proposed by the bill. This Point of Disagreement will be removed.
    1. Concern was expressed on intent behind attempt to remove the language.
    2. Daniel clarified that there was no malicious ill intent behind this and that while the bill composers may have gotten it wrong in making changes without consulting the CAG body, their intent was to do "housekeeping" – clean up language, modernize it, and recognize that HIPAA covers much of this, making the language redundant. He reiterated that this body can certainly communicate when something is perceived as an overstep, when CAG is not consulted.
iv. **Point of Disagreement with Bill**: #6 [Subdivision (e) (p7, line 7 through p9, line 2) regarding the retention of language on penalties for unauthorized disclosure] was discussed and identified as the heart of the biggest disagreement.
    1. Daniel confirmed that this language was originally written before HIPAA protections were passed.
    2. Discussion related to: what redress would remain available, the decision-making power of the judge in any such case mitigating the concerns about jail time for negligence, removal of criminal penalties regarding HIV disclosure, and the value of strong language with harsh penalty for discouraging such disclosures.
    3. The removal of criminal penalties for HIV/AIDS would leave in place language making it a misdemeanor, and leave the option of civil suit in place.
    4. Chuck clarified that in discussions with the lawyer, Englander did not raise concerns about penalties being too harsh, or discouraging people to get tested or into treatment; he focused specifically on the issue of "treating HIV differently than other infections."
    5. This section will remain in discussion with the state.
v. **Point of Disagreement with Bill**: #7 [Subdivision (f) (p8, line 16 through p8, line 14) regarding the retention of language on VDH storage of information on networked computers] was discussed and final agreement was to remove the language.
    1. Discussion was had regarding the statement reflecting CAG support of giving VDH more freedom to do what was needed, and that leaving the language in affirmed CAGs efforts to be supportive and positive.
    2. Daniel explained that the concerns expressed by the bill-writers was that naming HIV/AIDS in this line may set up other infections that aren't specifically named for different treatment.
    3. Deborah asked if simply taking the language out would serve the same end as putting it in – i.e., giving VDH permission/support to use networked computers.
    4. Jonathan expressed concern that without it spelled out, would GMCB have leeway to apply different standards to other diseases. Daniel clarified that this bill relates only to VDH, and GMCB and Corrections can operate as they wish.
    5. Peter asked about VDH current firewalls, encryptions, etc., and confirmed that there was no place that VDH would not be employing those safe-guards. Daniel confirmed, and stated that "HIV sets the bar" and as they have been asked to integrate HIV with other diseases, the HIV regulations now sets the bar for

everything else, and that VDH does indeed have military-grade encryption. Peter expressed that these protections written into the bill are great, but so weak compared to what VDH already does to protect information.

6. Grace expressed support for removing the language – the expectation is that VDH will change with the times, and that it makes things easier and more streamlined to pull that piece out and have VDH use their current protections, and have those protections evolve as needed. She stated she trusted VDH to continue to protect information at a high level, but we never know what the legislature will be in the future. Removing the language would keep us from having to revisit it with the legislature in the future.
7. Chuck agreed, but expressed that the real disagreement here was only that it was such a symbolic statement of expressing support for the VDH, that it was hard to say "just take it out." He expressed how after fighting for seven years to say "you can't do this," to turn around and now support it, it is an affirmation of the community advisory body to keep it in.
8. Straw poll indicated there was not strong feeling around the table about taking it out, and that many felt they would be willing to go either way on the issue. Quick show of hands indicated approval of removing the language.

vi. **Point of Disagreement with Bill**: #8 [Subdivision (i) (p9, line 3 through 8) regarding the retention of wording advising testing clients that positive tests are reported, and anonymous testing is available] was discussed, and there was agreement that the lines could be removed.

1. Discussion concerned the issue of barriers to testing and care, versus emphasizing to people that their test results are going to be reported.
2. Deborah spoke strongly in favor of maintaining the removal of the language, due to the many people who come to her office already in advanced stages of HIV, because their doctor did not test them. The doctors continue to say "I only have 15 minutes with any patient and I can't spend the time distinguishing between confidential, anonymous, reporting" and the end result is they simply don't offer or do the test at all. The bottom line is that the disease is reportable – we fought that battle and lost, and now we must do everything we can to remove barriers to people getting tested and getting into care. Removing this statement from the bill is not taking away people's option to get an anonymous test.
3. Daniel reported that they fund approximately 1,000 anonymous tests per year, and compared to confidential testing, Planned Parenthood conducts over 12,000 confidential tests per year. VDH funds $250,000 to anonymous testing and counseling, and it is contributing to 1,000 tests per year, and there is real question as to how much larger that number will get. Erin agreed, that data is consistently showing that more people are going to confidential testing.
4. Testers past and present confirmed – people have a very hard time understanding the anonymous/confidential split, and numerous people walk into anonymous testing every day ready to pull out their Social Security card, and assuming the number is going to be recorded.

vii. CAG Actions on H.98

1. Peter made a motion that the CAG express official support of removing objections to numbers 5, 7 and 8 (represented above as items II. d. iii., v. and vi.) on Chuck's summary page.
2. Deborah seconded the motion.
3. The motion was approved.

III. DISCUSSION ITEM #2: GENERAL FUND AND COMMUNITY IMPACT

a. Peter gave a summary of current issues.
    i. One month ago there was notice that a large cut to the general fund budget was going to be made -- $135,000 would be cut from HIV Services and Care. This cut all of the current Vermont tax payer contributions representing 28% of the total funding; the balance is pharmaceutical reimbursements.
    ii. Efforts to work directly with lawmakers to highlight negative community impacts of the cut were met with polite attention but no indications of action or expected changes.
    iii. There are potential solutions to the negative outcomes that are in discussion thanks to Erin and Daniel's participation on working on the results of the cuts.

b. Peter highlighted actions we can all take to get the language put back into the budget.
    i. PLEASE CALL YOUR LEGISLATORS.
    ii. Roy has been working with local constituents on talking to legislators on the impact this would have on people living with HIV. That is a tool we can all use when reaching out to our local lawmakers.
    iii. The impact was highlighted on Case Management, Emergency Assistance, PWA Retreat, and the Women's Retreat.
    iv. There are core components of care in the state that are affected by the budget cuts.

c. The potential solution Erin and Daniel are working on is trying to find monies that could target the services most affected.
    i. There is a Plan B being put in place to try to keep core services functioning. This will involve studying the services that are being cut to determine if they may qualify for other forms of funding.
    ii. This may require changes to some services, but the effort is worth undertaking to closely examine the services most impacted.
    iii. VDH has asked all the ASOs and CBOs to submit a detailed budget and services will be examined as compared to funding requirements of Ryan White.
    iv. Daniel explained that when the news reached the public and consumers, that was when it reached VDH as well. He expressed that the VDH does not have a role in the state budget processes and cannot comment on them. This will not solve all problems and all losses, but it is a good process when facing this cut.
    v. Jonathan flagged that as programs get reviewed, he would like to note that it often makes more sense to have a program that can be fully implemented and will function, rather than partial funding for a lot of small programs that cannot really function without more funding.
    vi. In Prevention, there has always been an RFP, but that has not been the case with Care. Is this a possibility for the future? That is something for CAG to think about and weigh in on. There is not currently a mechanism for CAG to have a say in Care funding and an RFP process could shift that.

d. The unfortunate concern was raised that while rebate dollars are currently robust, removing the $135,000 from the general fund sets a bad precedent for future years, and we cannot count on what the future rebates will be. It was agreed that we all know that if the general fund money goes away, it is unlikely to come back.

e. The topic of third party billing was raised, and Daniel is trying to look into that for agencies. He is having discussions with Medicaid.
    i. In Philadelphia they had a third party billing system for case managers.
    ii. There is a question as to how much money this would generate given agencies are small, and how much it would truly support the financial needs.

iii. Deborah said that they decided not to bill for Zpora because then patients had to pay copays.
iv. Daniel said that the CDC is pushing hard in this direction. Billing is a partial answer but it does compromise many things.
v. Erin said that this is an opportunity to revisit and relook at services and explore what may be possible. Ryan White money can cover copays.

f. It was agreed that looking at what comes out of the Needs Assessment will play an important role in this.
g. There was brief discussion about the difference between having options for care as opposed to consolidating under one or two options only. It was confirmed that consumers do indeed move and/or travel quite a distance to switch providers and ASOs, depending on their experiences.
h. Grace suggested consulting the expert lobbyist on approaches.
i. It was agreed that Chuck would draft a letter that the CAG could send expressing concern and that CAG is available for consultation, and will bring it to the next meeting for people to read.
j. The overriding concern was expressed that when the CAG was begun, it was stated that it would have teeth and have an advisory capacity, which seems to be slipping away and that is disturbing. The state promised to listen, and CAG needs to hold them accountable to do so. Even if they go in another direction, they need to listen to the concerns and advise.
k. It was mentioned that as a body we may have come to rely too heavily on the good will of the VDH, based on the excellent relationships with Daniel, Erin, and others.
    i. It may be time that the CAG needs to take a more assertive role on where it wants to go.
    ii. Daniel said that after the dust settles on these changes, CAG may want to make a statement to the VDH about what CAG's charge is in regards to services.
l. Jonathan specifically asked that the minutes reflect that the community recognizes and wants to emphasize the excellent service of Daniel, Erin and HASH department – their steadfastness and trustworthiness in working with the CAG and the interests of the consumers. It was very concerning and insulting that higher levels did not consult with the CAG, but CAG feels listened to and supported by the HASH department.

IV. BUSINESS RESUMPTION

a. Public Comment:
    i. Vermont CARES has a new needle exchange in Rutland! This is great news and the result of long, hard work over ten years. Thanks for the continued efforts!
    ii. Alex reported that April 30 is the HARD DEADLINE for data collection in the Needs Assessment. There are still pockets that we would like more reach into, including Rutland, the Northeast Kingdom, and White River Junction. He will be contacting people.
    iii. Daniel mentioned a Hepatitis C Advocate Training in Washington DC to train Caring Ambassadors, May 10 – 13. There are spots for two individuals to be trained. It would be great to have providers represented, and consumers. Jonathan and Paul III expressed interest.
b. Community Concerns:
    i. Folks asked that the tables be reset side by side in the other half of the room. Alex expressed that the Wilder Center was trying to be responsive to the needs of the group in extending the tables in the current direction, to allow for easier movement and less crowding.

Respectfully submitted,
Alexander Potter, Center for Health and Learning