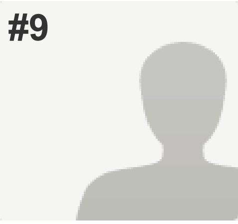

#9

COMPLETE

Collector: Web Link (Web Link)
Started: Wednesday, October 29, 2014 3:57:36 PM
Last Modified: Wednesday, October 29, 2014 4:37:05 PM
Time Spent: 00:39:28
IP Address: 50.75.234.202

PAGE 1

Q2: **Title of your recommendation**

Community-based Education for People with HIV

Q3: **Please provide a description of your proposed recommendation**

Increased funding for statewide community-based education for people with HIV. Regular workshops are needed on HIV treatment, drug resistance and adherence, understanding lab results, HIV transmission, and other medical topics.

Q4: **For which goal outlined in the Governor's plan to end the epidemic in New York State does this recommendation apply? (Select all that apply)**

Linking and retaining persons diagnosed with HIV to health care and getting them on anti-HIV therapy to maximize HIV virus suppression so they remain healthy and prevent further transmission

Q5: **This recommendation should be considered by the following Ending the Epidemic Task Force Committee (Select all that apply)**

Care Committee: Develop recommendations to support access to care and treatment in order to maximize the rate of HIV viral suppression. The Committee will promote linkages and retention in care to achieve viral suppression and promote the highest quality of life while significantly decreasing the risks of HIV transmission. Recommendations will also ensure a person centered approach is taken and that access to culturally and linguistically appropriate prevention and health care services is available.

Q6: **Does this recommendation require a change to an existing policy or program, or the creation of a new policy or program?**

New program

Q7: **Would implementation of this recommendation be permitted under current laws or would a statutory change be required?**

Permitted under current law

Q8: **Is this recommendation something that could feasibly be implemented in the short-term (within the next year) or long-term (within the next three to six years)?**

Within the next year

Q9: What are the perceived benefits of implementing this recommendation?

I have been a community-based HIV educator for close to 25 years. In that time, I have been astounded by the continuing amount of misinformation and disinformation that I encounter.

"HIV meds will kill you faster than HIV."

"I take only half my HIV meds in order to protect my liver."

"Magic Johnson gets special meds that we can't get."

These mistaken beliefs prevent people from entering into care, discourage them from starting treatment, and make it more difficult for them to stay virally suppressed.

Even if we identified every person with HIV in New York, even if we got every one of them into care, and even if the drugs were free, we would still not achieve the over 80% viral suppression needed to end the epidemic, because people must understand the why and the how of the meds in order for them to work.

Community health education is the key. It goes into communities and provides information at understandable literacy levels. Health information is communicated in ways that are clear and that are able to be evaluated. Effective health communication uses plain, but not “dumbed-down,” language. Its information people can understand the first time they read, see, or hear it. It helps them find what they need, understand what they find, and use it to meet their needs.

Research has shown that health literacy is a significant factor in the health of people with HIV. People with HIV who have lower health literacy have lower CD4 counts, higher viral loads, are less likely to be taking HIV medications, have more hospitalizations, and are in poorer health than those with higher health literacy. Lower health literacy is associated with poorer knowledge of HIV-related health status, poorer AIDS-related disease and treatment knowledge, and more negative health care perceptions and experiences.

Some feel that this information should only be provided by health care providers, but my experience has shown that they are often not the best educators. Lack of time is a key problem: my workshops generally run two hours - something that no doctor could afford to do. In addition, I have found that many great doctors are not great educators - providing excellent health care requires a very different skill set than teaching health information. Shorthand, acronyms, and jargon are common when speaking to clinicians, and explanations are often not effective. In addition, many patients will not ask questions of clinicians, because of embarrassment at not being able to understand the information or for cultural reasons related to dealing with authority figures. Peers and community-based educators can establish a more equal relationship that allows for a more open exchange of concerns. I've had clients who admitted to me that they were not taking their HIV meds, even though their entire medical care team thought they were.

Community health educators are key to solving this problem. They are teachers, not busy health professionals, and are trained to translate difficult medical concepts to laypeople. In addition, learning this information in a group setting is powerful - many times, I have seen participants learn much from other people with HIV during my workshops. Information gained from peers is a strong weapon against rumor and myth.

There are a number of CBOs across the State with experience in health literacy who could provide workshops quickly and effectively.

Q10: Are there any concerns with implementing this recommendation that should be considered?

NYS should ensure that educators are well-trained and provide science-based, accurate information while refraining from offering medical advice.

Q11: What is the estimated cost of implementing this recommendation and how was this estimate calculated?

Based on my experience as an educator, a statewide training initiative, offering regular workshops, run by multiple CBOs, would require somewhere close to $500,000 annually.

Q12: What is the estimated return on investment (ROI) for this recommendation and how was the ROI calculated?

Don't have a number, but I firmly believe this is an essential component of increasing the number of people who remain virally suppressed.

Q13: Who are the key individuals/stakeholders who would benefit from this recommendation?

People with HIV and their partners

Q14: Are there suggested measures to accompany this recommendation that would assist in monitoring its impact?

All workshops should be evaluated by participants, including using pre- and post-testing to gauge their effectiveness.

Q15: This recommendation was submitted by one of the following

Advocate