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Collector: Web Link (Web Link)

Started: Thursday, October 30, 2014 2:54:28 PM **Last Modified:** Thursday, October 30, 2014 3:36:24 PM

Time Spent: 00:41:55 IP Address: 64.61.84.122

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Q2: Title of your recommendation

Guaranteeing Minors the Right to Consent to HIV Treatment & Prophylaxis

Q3: Please provide a description of your proposed recommendation

NYS should amend Public Health Law, Article 27(f) ("HIV and AIDS Related Information") to allow for minors to consent to their own HIV treatment and prophylaxis.

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)

Identifying persons with HIV who remain undiagnosed and linking them to health care

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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

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Facilitating access to Pre-Exposure Prophylaxis (PrEP) for high-risk persons to keep them HIV negative

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?

Change to existing policy

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

Statutory change required

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?

In New York State, a competent minor may consent to both STI and HIV testing without the need for parental consent. The law further allows minors to consent to STI treatment, but for good reasons HIV is not included in the definition of STIs for these purposes. Statutory law, with a few exceptions, fails to guarantee minors the right to consent to their own confidential care and treatment for HIV/AIDS.

This legal bind-- that minors may be tested, but are not guaranteed the right to confidential treatment under state law -- forces young people who are unable or unwilling to disclose their HIV status to an adult authorized to make their health care decisions to forego treatment, a cruel outcome for someone newly diagnosed. Some young people are also less likely to get tested if they know that obtaining treatment is only possible with parental notification and consent. A statutory scheme that allows a minor to consent to testing but not to treatment fails to meet the critical health needs of this essential population. The proposed recommendation would remedy this shortcoming, and would allow minors to access the care they need, particularly if the state simultaneously takes action on the related recommendation regarding regulation of Explanation of Benefits forms for dependents.

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

Some constituents/stakeholders might raise concerns about a parent's right to be involved in his/her child's health care.

There may be concerns about whether a young person can maintain a care and treatment regimen without the support of an involved parent.

Solving the consent issue without solving the related Explanation of Benefits (EOB) confidentiality problem will not fully free many minors to access confidential care.

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

Outreach to providers regarding changes in the law.

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

*Savings associated with receipt of early treatment by those who might have delayed treatment until they reach the age of majority, and could consent to their own care, including reduction in ongoing transmission.

*Savings to hospitals and healthcare providers who must currently spend time determining how to remain within the letter of the law – work that would be unnecessary if minors were allowed to consent to their own care.

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

- Youth
- Adolescent health care providers and their institutions
- Parents
- LGBT youth service providers
- · Foster care administrations and agencies

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

- Meeting of appropriate parties to determine legislative language and placement.
- Create outreach materials for providers and adolescents about the change in the law.
- Inclusion of legislative language in budget bill.
- Subsequent to passage of language (approval of budget), inform adolescent healthcare providers and caregiving institutions, as well as adolescents themselves about the change in the law.
- Percent of minors with a positive HIV test who are linked to and retained in HIV care.

Q15: This recommendation was submitted by one of the following

Other (please specify)

Ad Hoc End of AIDS Community Group: ACRIA, Amida Care, Correctional Association of New York, Jim Eigo (ACT UP/Prevention of HIV Action Group), GMHC, Harlem United, HIV Law Project, Housing Works, Latino Commission on AIDS, Legal Action Center, Peter Staley (activist), Terri L. Wilder (Spencer Cox Center for Health), Treatment Action Group, VOCAL New York