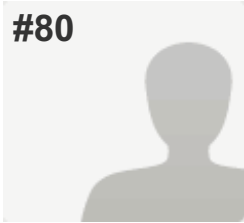


#80

**COMPLETE****Collector:** Web Link (Web Link)**Started:** Friday, October 31, 2014 1:36:39 PM**Last Modified:** Friday, October 31, 2014 2:00:24 PM**Time Spent:** 00:23:44**IP Address:** 64.61.84.122

PAGE 1

Q2: Title of your recommendation

Introduce Stigma Measures For Healthcare Providers, the General Population and People Living With HIV

Q3: Please provide a description of your proposed recommendation

New York State (NYS) and New York City (NYC) should include questions that measure HIV-related stigma and discrimination, and intersecting stigmas in care- and service settings (including homophobia, transphobia, sexism, racism, and biases against immigrants) in regularly occurring surveys until 2020. Existing reliable HIV-related stigma measures should be used for healthcare workers, the general population, and people living with HIV (PLHIV). Specifically, "Measuring HIV Stigma and Discrimination among Health Facility Staff: field-tested questionnaire" by the Health Policy Project, the general population stigma survey developed by the International Center for Research on Women, and the "People Living with HIV Stigma Index." These three surveys were created to include similar questions on specific domains of stigma and can be used to triangulate results (see Measuring Stigma and Discrimination: A Technical Brief by Stangl, A; Brady, L; and Fritz, K. (2013)).

New York State should implement the People Living with HIV Stigma Index project (Stigma Index) in partnership with networks of people with HIV and community-based organizations to measure HIV-related stigma and discrimination as experienced by people living with HIV and to identify the most effective systemic changes that will link and retain people in quality medical care, ensure viral load suppression, reduce mortality, and increase the quality of life of people with HIV.

- See www.stigmaindex.org
- Dos Santos, M.M. et al.(2014). An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the People Living with HIV Stigma Index. BMC Public Health. 2014 Jan 27;14:80. doi: 10.1186/1471-2458-14-80.
- Grossman CI and Stangl AL. (2013). Editorial: Global action to reduce HIV stigma and discrimination. Journal of the International AIDS Society 2013, 16(Suppl 2):18881
- Aparna, J. et al. (2013). Community-based interventions that work to reduce HIV stigma and discrimination: results of an evaluation study in Thailand. Journal of the International AIDS Society 2013, 16(Suppl 2):18711
- SeyedAlinaghi, S. (2013). Evaluation of Stigma Index Among People Living with HIV/AIDS in Six Cities in Iran. Thrita. 2013 November; 2(2): 69-75.
- Sprague, L., Simon, S., & Sprague, C. (2011). Employment discrimination and HIV stigma: survey results from civil society organisations and people living with HIV in Africa. African Journal of AIDS Research, 10(sup1), 311-324.
- Holzemer, W.L. et al. (2007). Validation of the HIV/AIDS Stigma Instrument - PLWA (HASI-P). AIDS Care. 2007 Sep;19(8):1002-12.

Ending the Epidemic Task Force Recommendation Form

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

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.

Data Committee: Develop recommendations for metrics and identify data sources to assess the comprehensive statewide HIV strategy. The Committee will determine metrics that will measure effective community engagement/ownership, political leadership, and supportive services. It will also determine metrics that will measure quality of care, impact of interventions and outcomes across all populations, particularly identified sub populations such as transgender men and women, women of color, men who have sex with men and youth. In addition, the Committee will evaluate to determine optimal strategies for using data to identify infected persons who have not achieved viral suppression and address their support service, behavioral health, and adherence needs.

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 three to six years

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

HIV-related stigma and discrimination are repeatedly identified as key barriers to ending the epidemic, whether in healthcare, employment, the legal system, education, or access to public services. In healthcare, every point along the HIV Care Continuum is affected negatively by stigma and discrimination. People report that they fear being seen testing for HIV or accessing medical care; they fear rejection from family and friends; they fear losing their jobs; and they fear physical violence. Failing to address stigma and discrimination not only keeps people from health care services, it makes HIV treatment less effective even when it is accessed. If the plan to end the AIDS epidemic in New York State by 2020 is to succeed, an effective measure for HIV-related stigma must be included in the Plan.

To address HIV-related stigma and discrimination, reliable data is needed on its incidence, extent, and locations for different affected populations. The Stigma Index and measures of stigma for healthcare workers and the general population would provide this data.

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

Strict confidentiality protocols will be required for participants in Stigma Index interviews.

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

Costs associated with introducing stigma measures for healthcare workers and the general population. The Stigma Index is scalable and its costs include: project management, training of interviewers, conducting interviews, interview stipends, travel costs, data entry and analysis, capacity building and training for people with HIV, community mobilization (to identify needed systemic changes), development of recommendations and programs. If NYS were to implement this program costs would be shared with community stakeholders and foundation grants.

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

Studies to determine ROI for stigma interventions are rare and use different calculation methods (see examples below). However, a positive ROI is expected both for the health effects of getting and keeping people in care and the social effects of improved access to employment, services, education, and community networks.

Expected measurable outcomes include: increased uptake of HIV testing, treatment, and care services, resulting in lower viral load, morbidity, mortality, and transmission; and increased employment, housing, and other quality of life measures for people with HIV.

In New York, Brent (2013) calculated the value for each point reduction in stigma (using Berger's 2001 scale) at \$1000 per person with HIV. To illustrate, if 50 people saw a reduction in stigma by 5 points (on a 120 point scale), the value would be \$250,000. (Brent, R.J. 2013. The Value of Reducing HIV Stigma. Fordham University, Department of Economics Discussion Paper No: 2013-05.)

An evaluation of the social return on investment (SROI), which includes social, economic and environmental costs, of stigma reduction activities in Zambia found the value over five years ranged from 1:14 to 1:21. (International HIV/AIDS Alliance. 2011. The true cost-Evaluating the Social Return on Investment of the stigma and discrimination component of the Alliance's Africa Regional Programme II. Hove, UK:IHHA.)

Modeling in South Africa and India indicates that early ART initiation saves \$590 and \$530, respectively, per life year saved by improving the health of the person with HIV and reducing onward transmission. (Walensky, R.P. et al. 2013. Cost-Effectiveness of HIV Treatment as Prevention in Serodiscordant Couples. N Engl J Med 2013; 369:1715-1725.)

Ending the Epidemic Task Force Recommendation Form

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

People living with HIV, particularly those not linked to services or retained in quality care, those at risk of falling out of care, and those with undiagnosed HIV.

Racial and ethnic minorities, young people, women, LGBT people, immigrants, people who are incarcerated, people who use drugs, and sex workers.

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

Measure and changes in health, quality of life, self-efficacy, and internalized stigma experienced by people living with HIV who and measure the efficacy of interventions. Measure healthcare worker stigma and HIV-related stigma in the general population.

Set interim stigma targets. The target for 2020 should be zero stigma.

Q15: This recommendation was submitted by one of the following

Advocate,

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