



**Strategy Lab Call  
As Health Care Reforms Move Forward,  
Will HIV Prevention and LGBT Health Be Left Behind?**

**March 18, 2009**

**Speakers:**

David Holtgrave, PhD, Johns Hopkins University  
Rebecca Fox, National Coalition for LGBT Health

**Moderator:** David Munar, AIDS Foundation of Chicago

**Materials Referenced:**

- "HIV Incidence and CDC's HIV Prevention Budget: An Exploratory Correlational Analysis," David R. Holtgrave, PhD and Jennifer Kates, MPA, American Journal of Preventative Medicine, Volume 32, Issue 1, 2007. To receive a copy of this article, email [dholtgrave@jhsp.h.edu](mailto:dholtgrave@jhsp.h.edu) or [josh@champnetwork.org](mailto:josh@champnetwork.org)
- "Guiding Principles for Lesbian, Gay, Bisexual and Transgender Inclusion in Healthcare Reform," National Coalition for LGBT Health, [http://www.lgbthealth.net/documents/LGBTGuidingPrinciplesFINAL\\_000.doc](http://www.lgbthealth.net/documents/LGBTGuidingPrinciplesFINAL_000.doc)

**Overview of Call (David Munar)**

As health care reform moves forward, will HIV prevention and LGBT health be left behind? We will consider how to advance prevention justice, HIV prevention, and public health agendas as well as LGBT health needs in health care reform.

- Health care has gained momentum; President Obama is committed to advancing a health care reform initiative this year.
- Congressional committees already have begun work, including Congressional leaders such as Kennedy and Baucus, who are looking at financing and delivery of health care -- with the particular aim of expanding coverage.
- How we as advocates frame this discussion from our prevention justice framework?
  - o Ensure that populations most affected by and at risk of HIV receive services from this expansion.
  - o Public Health should also receive attention.

**Dr. David Holtgrave, Chair, Department of Health, Behavior and Society at The Johns Hopkins School of Public Health**

Articles referenced:

- "HIV Incidence and CDC's HIV Prevention Budget: An Exploratory Correlational Analysis," David R. Holtgrave, PhD and Jennifer Kates, MPA, *American Journal of Preventative Medicine*, Volume 32, Issue 1, 2007. To receive a copy of this article, email [dholtgrave@jhsph.edu](mailto:dholtgrave@jhsph.edu) or [josh@champnetwork.org](mailto:josh@champnetwork.org)
- "Health Prevention as a Priority: Creating a 'Wellness Trust'", Jeanne Lambrew and John Podesta, *Washington Post*, 10/17/2006, <http://www.washingtonpost.com/wp-dyn/content/article/2006/10/16/AR2006101600880.html>

**Overarching theme:** How do we make an argument for HIV prevention in an era when healthcare reform drives the discussion in weeks, months, and years ahead?

- (1) What are the characteristics of healthcare reform set out in the Obama campaign and now in the first few weeks of the new Administration? What do they believe will be successful healthcare reform?
- (2) Are arguments for HIV prevention consistent with those characteristics of successful healthcare reform?
- (3) Crafting an argument for HIV prevention around "legacy" - thinking about a 2-term presidency and what could be accomplished. What would be the lasting legacy of President Obama's administration around the HIV epidemic?
- (4) Advocacy comments. How can we craft, build constituencies, and move forward some of these arguments for prevention in this era of healthcare reform?

**(1) Characteristics of healthcare reform: what have they been?**

A review of Obama/Biden campaign materials specify characteristics of healthcare reform to be:

- Lower costs
- Improve access to prevention
- Comparative effectiveness reviews and research
- Tackle health disparities
- Reduce cost of catastrophic illness to employers and employees
- Promote prevention and strengthen public health simultaneously with improved access to clinical care

Since President Obama took office, the White House website repeats these characteristics. A special point is made to say that the Obama-Biden plan will promote public health, and it will require coverage of preventative services.

In national community healthcare forums, 30,000 participants discussed how healthcare reform would impact their lives. Healthreform.gov lists top concerns of community healthcare discussion participants; the third highest-rated concern was lack of emphasis on prevention and preventative services.

On the White House website under civil rights and LGBT issues, there is a whole section devoted to HIV prevention, including access to preventative services, evidence-based sex education, and lifting the ban on syringe exchange.

## **(2) Arguments for HIV prevention consistent with those principles:**

- **Comparative effectiveness research:** We have very strong studies that look at individual interventions
- **Cost-savings:** Many studies show intervention are cost-effective and cost-saving in HIV prevention for several prevention tools. It is true of individual, small group and interventions generally. If we look at the transmission rate in the US (the number of new infections divided by prevalence every year), we see an 85% drop since the mid 1980s, and it has dropped about 1/3 since 1997.
- **Low transmission rate:** It is now 5 or lower - meaning that for every 100 persons living with HIV, there are only about 5 transmissions in a given year. This is important evidence around prevention effectiveness.
- **Increased investment yields lower incidence:** Dr. Holtgrave published a paper with Jen Kates (Kaiser Family Foundation) on the relationship between investment in prevention and incidence, showing that these two things are mirror images of each other. As we invest more, we do better with new infections in the US.

**Summary:** These arguments around the evidence for prevention and the cost-savings of prevention are consistent with characteristics of healthcare reform outcomes:

- (1) Increases access to preventative services,
- (2) Saves money, and
- (3) We have good comparative effectiveness literature.

## **(3) Legacy for new Administration**

It's not too early to think about this.

In September 2008, Rep. Waxman held a hearing about HIV prevention in the US. Holtgrave gave testimony on how much would we need to invest to make a big difference in the US in regard to infections and transmission rate.

Based on analyses by Johns Hopkins researchers, and with the following conditions,

- One year of planning
- Then investing \$1.3 billion/year on prevention (which is more than CDC's ~800 million/year...an increase of \$500 million for US prevention) over course of several years
- Barring no new discoveries in evidence-based prevention

- Using only interventions we now have at hand (counseling & testing, prevention with positives, for prevention for persons at risk of becoming infected)

...we can increase awareness of seropositivity to 90% and reduce transmission rate from approximately 5/year to about half, and reduce incidence by about half in a five year timeframe. There would be a time lag, however, after that period before it could be measured to ensure that we achieved those goals (so we would not know immediately after that whether those goals were achieved; but Dr. Holtgrave thinks it is achievable).

What if we don't achieve that level of scale up; what if we don't make that level of investment?

- We can show over that 5-year timeframe an additional 89,700 extra infections that could have been prevented and 1350 more deaths -- all because we did not choose to scale-up.
- The public sector lifetime care and treatment costs discounted into present value, there would be about \$18.5 billion extra medical costs -- the financial consequences of choosing not to scale up.

**Summary:**

- Comparison of the scale-up scenario to business-as-usual results in substantial extra numbers of new infection and death -- and the nation pays for the "privilege" of having that occur.
- Bottom line: More infection, more death, more cost.
- Comparing those two pathways, which legacy would the new Administration like to have 8 years from now?
  - o A pathway showing substantial progress in the epidemic?
  - o Or a pathway showing more of the same and allowing this opportunity go by?
  - o And, choosing not to spend more money on prevention really means that were going to choose more money on public sector care and treatment down the road.

**(4) Arguments around advocacy**

If there are two pathways ahead of us:

- (1) Increasing investment and making a bigger difference in the epidemic
- (2) ...or not.

Pathway #1 would also be consistent with the principles for healthcare reform laid out in the campaign. The argument:

- (1) **Appeal to rationality:** Make these points over and over again - and appeal to these and other arguments for prevention and why prevention is related to healthcare reform.
- (2) **Insist on promise fulfillment:** How fast can the promises listed on the White House website be fulfilled?

**(3) Compare the level of investment in prevention to what is spent on earmarks or other changes in the budgets:**

- a. The stimulus allotted \$400 million for prevention, but did not pass (though there is hope that \$600 million budgeted for chronic disease would come to HIV, but that is a big question).
- b. In the omnibus bill there is a scant increase for HIV prevention and there is a promise in the FY10 top line (but we don't know what that means in dollar terms). In the omnibus, Congress itself increased its operational budget from \$4 billion/year to \$4.4 billion/year (source: AP)...well there's the \$400 million right there. So \$400 million was found for operating Congress, but it was not found for HIV prevention.

**(4) Engage public health allies** that could be a part of the coalition (Association of Schools of Public Health, American Public Health Association) and other partners that share an interest in how HIV prevention relates to health care reform who might be potentially natural allies.

**(5) Wellness trust proposal:** Look at proposals put forward from Center for American Progress for a "wellness trust" – in which the government sets aside healthcare reform monies to fund surveillance and public health activities, prevention services and things going beyond clinical HIV prevention and clinical services. It is important to have clinical and community-based services, too. This wellness trust idea might be a mechanism to do that.

**Rebecca Fox: LGBT issues in health and what the emerging debates mean for achieving better outcomes in LGBT communities.**

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Material referenced:

“Guiding Principles for Lesbian, Gay, Bisexual and Transgender Inclusion in Healthcare Reform,” National Coalition for LGBT Health,  
[http://www.lgbthealth.net/documents/LGBTGuidingPrinciplesFINAL\\_000.doc](http://www.lgbthealth.net/documents/LGBTGuidingPrinciplesFINAL_000.doc)

Healthcare reform is happening quickly. Hill staffers report that they will have this out of Senate by August recess. How much this will be about healthcare financing versus healthcare delivery remains to be seen. They are planning to do a big push on this.

The National Coalition for LGBT Health - with some allies - put together a document to talk about the ways LGBT healthcare issues are just like everyone else's - and how they are different. This is a pivotal moment for the LGBT community. It would be a revolutionary moment for LGBT community if there would be a major federal government buy-in for LGBT. This document is aimed at practical solutions for LGBT care.

Unlike other subpopulations, there is no good federal health data on the LGBT

community. LGBT is routinely left out of large scale surveys and evidence-based practices. There are no demographic questions for the LGBT community. To show how to save money via prevention and healthcare, the LGBT advocates have to rely on small-scale studies. This document, in part, advocates for LGBT inclusion.

[Health Care for America Now](#) is a great coalition to get involved in - it includes the big unions and is the big progressive voice around healthcare reform. It is debating these issues internally before a big external rollout.

### **LGBT access to care: what it would look like**

- **Having guaranteed access to care:** Whenever a new administration comes into office, LGBT people face losing rights. For instance, lesbians could access in vitro fertilization under the Obama administration...but a "Bush III" administration could come in and we would not be able to access anything. Therefore, when setting up a large federal delivery mechanism, there needs to be a non-partisan body in place that is not impacted by changing administrations. This concern is shared with choice and women's groups.
- **Inclusive definition of family:** Definitions of family currently existing in federal regulations exclude LGBT families. If there is going to be health care that includes health IT and national standardization of forms, there needs to be fields for "partner" and "second parent adoption" so that LGBT people have access to their families and family medical records in times of crisis.
  - o The National Coalition for LGBT Health is working with a coalition of women of color groups to push forward changes around family definitions.
  - o DOMA - the Defense of Marriage Act - is a burden for the LGBT community. DOMA forbids the federal government from recognizing our unions. How is it possible to enact health care reform that recognizes LGBT without violating federal law?

### **Other issues to address in health care reform:**

- **Pre-existing conditions:** LGBT people are more likely to have them. Health care should not exclude for pre-existing conditions...there should not be a 6 month or year-long waiting period until basic things are covered.
- **Mental health parity:** Important for LGBT people (that is equal coverage for mental and physical health).
- **Cultural competency:** Health care providers need to know unique risks and overlaps faced by the different LGBT people; for instance, ensuring that providers know what it means to be both African American and gay (and what that means for prevention, health care, delivery).
- **Health IT:** Raises privacy concerns. In many medical settings it does not matter if someone is transgender, but nevertheless in many settings a transgender person

could be treated differently, denied care, and even die in care. What does it look like to have health IT that does not allow LGBT community to be discriminated against?

- **Data collection issues:** Need to start collecting the evidence on the LGBT community. For many people living with HIV and prevention efforts - there is a changing medical landscape. As new drugs for treatment and new tools/interventions for prevention become available, what does that look like? How do we push forward new and best practices lacking many years of evidence to support them?
- **Transgender inclusion in health care:** In order to get most forms of medically related transition services, one needs a diagnosis of Gender Identity Disorder. The majority of private and public insurance companies summarily exclude any kind of transgender-related coverage. Very rarely this exclusion has to do specifically with sex reassignment surgery or hormones. Insurance expand it out to mean anything: mental health care (e.g., we don't know what hormones do to mental health...if someone has a pre-existing condition that could be related to being transgender, they will exclude that too).
- **Reproductive health care:** If heterosexual couples are able to access in vitro fertilization or other forms of family creation, then the LGBT community must be included. There must be non-discrimination clauses to allow LGBT people to access this care.
- **HIV/AIDS:** Especially around gay, bi men, transgender persons, especially people of color and transgender women, and the increased risk for these communities. If health care reform is going to embrace a prevention strategy, then it needs to move away from a fear of talking about sex and the reality of people's lives. Health care must meet people where they are.

## Discussion and Q&A

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**David Munar:** As we hope we move towards a system with more federally-funded health care coverage, including expansion of Medicaid and Medicare, what would that kind of reform mean for CBOs, particularly LGBT organizations and others that are instrumental for the delivery of HIV prevention activities (individual and structural)? How does a new financing system that really emphasizes coverage might be an opportunity to do broader public health and community advocacy work? Could that also shift away from CBOs?

**Rebecca Fox:** In conversations with senate staffs, there was conversation about how organizations depend on the way Ryan White Care Act funds organizations now, and they say that they have no plans at this time to dismantle that system.

**David Holtgrave:** One important issue will be what the services are provided for coverage (which would be more clinical), and working to expand the definition of what

are covered preventative services. Another issue goes back to the wellness trust idea. If it is tied to the size of Medicaid and Medicare expenditures and that some percentage goes into a set-aside, even as there is growth in Medicare and Medicaid, a proportional fraction goes to this trust. Then, it could be used to ensure funding for health department-related and CBO activities. This set-aside would be an important insurance policy. There should be funding for CBOs in the main body of these covered services, but it is important to have these funds for public health too. This idea is championed by the Center for American Progress (see Washington Post editorial by Jeanne Lambrew and John Podesta in October 2006), and they have close ties to the Administration.

**James Learned:** What are pre-existing conditions specific to LGBT communities?

**Fox:** Higher rates of HIV, mental health concerns, ovarian and breast cancers. Pointing out these pre-existing conditions is more than just about exposing them. It is also a strategy of showing that LGBT health concerns fit into larger health concerns.

**Dan Wohlfeiler:** What is the future of screening guidelines, HEDIS measures to enforce strategies, for example that sexually active women to get annual Chlamydia screening. But what are the leverage points to ensure that HIV, STDs and hepatitis screening be included and covered?

**Holtgrave:** If there is a conversation around comparative effectiveness research (not clear how that will happen), the first step is marshalling the evidence around screening programs. There is a lot of evidence to be pulled together and critiqued. How does this compare to other places where money can be spent? Since it would probably compare favorably, the question turns to how to move beyond the comparative effectiveness and guidelines to actually ensure it gets covered (that's another point of advocacy).

**Fox:** There is talk of formalizing and adopting the recommendations of the US Public Health Service task force. That is a place of leverage. There is pressure to cover gender-specific care; however, that does not work for everyone. For instance, if one has a male marker for gender identification, then it is hard to get a pap smear. For gay and bisexual men, the need for anal paps don't fit into typical prevention services. In order to get this into the public dialog and in front of the US PHS Prevention Task Force, the National Coalition for LGBT Health will put out a paper on the state of prevention services for LGBT people, focusing especially on transgendered persons.

**Richard Kearns:** Gay male PWAs living in assisted care is growing. Most men with AIDS live alone without family support and depend on the assisted care system. This is an important consideration that should be considered in this dialog.

**Julie Davids:** When talking about how definitions of family leave out many aspects of LGBT families, are major family-oriented health coalitions working as good allies on this, and/or do you anticipate organized push-back from the religious right or other vested health care interests in having better definitions that won't exclude us or our family members from care?

**Fox:** It is fair to assume that there will be major pushback on any change or broadening

the definition of the family. While this seems obviously to be a LGBT issue, it is really much larger than that. The majority of Americans do not live in a nuclear household, and many do not want to. What does that mean to access larger kinship networks and things of that nature? The National Coalition has done a lot of work with women of color groups specifically because of them having the same exact issues. They are reaching out to family-centered groups to invite them to come on board with this.

**Carey Johnson:** What do we anticipate of the opposition's messages – and of their backlash?

**Fox:** This is another move to take away traditional family structures; that the LGBT community is so small or minor that we should not think about it. In addition to worrying about the obvious enemies, we should also worry about mainstream health care reform movement not being aware of these things. Therefore, we need to work in larger coalitions with people who have more powerful voices than us to carry the message or slip our messages in theirs. Our voices are not big enough in this fight; we need to add ours to theirs.

**Holtgrave:** What happened to in the stimulus package was instructive. It started at \$335 million in the house and increased to \$400 million in the Senate. In negotiations to garner 60 votes in the Senate, STD/HIV/hepatitis money was highlighted for comment in the news media. The coverage portrayed HIV in the US is not a problem, or that we know how to do prevention for free and don't need expensive prevention programs. Those arguments, however sad, could have been anticipated. Equally troubling is that the money was a chip to be negotiated away, and there was not outcry about it. So, we have seen the backlash and its response in the stimulus issue, and it is very disappointing.

**Fox:** We need to all have the same firm line on the necessity of all these services.

**Holtgrave:** We need to find organizations that have issues in common, and make it as broad as possible.

**Munar:** How much of this debate will be in the Congressional arena, and how much would we want to have it in the regulatory level? The first big challenge in Congress is the financing debate about how much money is needed for the types of expansion being discussed and where it is going to come from?

**Fox:** The financing parts will be the major roadblock. There will be a need to prove why certain treatment and management strategies work for people living with HIV. Though we have a friendly Administration with friendly appointments, we ignore Congress at our own peril.

**Clarence Charles:** How will we address issues of discrimination that result in barriers to care?

**Holtgrave:** The UCLA Law School did a study in which a person identified as living with HIV called service providers and asked to be seen. Also, a person posing as a

physician made referral calls. Over 300 service providers were contacted, including plastic surgeons, skilled nursing facilities and Ob/Gyns. About 1/4 of plastic surgeons, 45% skilled nursing facilities and 55% of Ob/Gyns declined the referral. This level of stigma among health care providers is quite high - so including this issue in health care reform is a critical opportunity.

**Comment:** Has the HHS Refusal Rule (allowing individuals and institutions the ability to refuse care that does not correspond to their religious or moral beliefs) enacted in the final days of the Bush Administration been revoked?

**Catherine Hanssens:** The conscience regulations have been put on hold and rescinded pending further comment. Lambda Legal and other organizations will draft more comments. The current Administration is revisiting the issue and we can expect that the regulations will be modified. Regarding refusal to treat, this is widespread. The ADA and the Rehabilitation Act of 1973 make this illegal. GLADD, Lambda Legal and other organizations have pursued litigation on these issues - so it is important to notify legal services organizations when these cases arise.

**Hanssens:** Question - the refusal to treat issues relates to the need for provider education around patient-centered care and provider literacy for HIV care. Is there a place for this in health care reform? Financial incentives of health care reform could ensure that doctor-patient communication is covered.

**Holtgrave:** Medical education should consider elements of medical school curricula to ensure that these issues are emphasized. NIH has \$10 billion in challenge grants (2-year grants for behavioral and social topics), and this research funding could be used to test training programs and build doctor-patient communication.

**Munar:** Health care reform is a multiyear - even decade-long - effort. The ways health care expansion will impact public health, community agencies, quality and education of clinicians will take a while. We know that it took a long time to get the expansion of Medicare for prescription coverage, and even longer to make it work once it was in place.