

TOWARD A VISION OF THOUGHTFUL CHANGE, MIAMI

A THINK TANK EXPERIENCE

FEBRUARY 17-18, 2009

REPORT OF PROCEEDINGS

COMMISSIONED BY

MIAMI-DADE COUNTY HEALTH DEPARTMENT

Submitted by:
S&H Consulting, LLC
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TOWARD A VISION OF THOUGHTFUL CHANGE, MIAMI FORWARD



EVELYN ULLAH, B.S.N., M.S.W.
DIRECTOR, HIV/AIDS PROGRAM

"I just want to convey about this conversation, it's a conversation that's long overdue. That we could continue in the same manner we've been going and be satisfied with the status quo, or we can really think collectively and think big and strategically and talk about where we need to go."

* * *

"This is my burning passion. It is my burning passion because I have four close family members who succumbed to this tragic disease early on. And I saw the tremendous impact it had on my family. And I saw the ramifications it had on my community. And that's something that is forever embedded in my mind. I can close my eyes and clearly visualize the year 1982, working at Lincoln Hospital on the medical floor . . .The rooms were extremely dirty. They were dark and morbid. The food tray was left outside the patient's room. There was a deluge of garbage strewn all over the floor. There were, you know, health care providers that just flatly refused to treat that person. And so that motivated and drove me to stay and fight this epidemic."

Evelyn Ullah, BSN, MSW
February 17-18, 2009



Introduction

For two days in February 2009, more than 30 invited participants attended a Think Tank, *Toward A Vision of Thoughtful Change, Miami*. Evelyn Ullah, BSN, MSW, Director of the Miami-Dade County (Miami-Dade) Health Department, Office of HIV/AIDS, convened the Think Tank, with sponsorship from the California-based Flowers Heritage Foundation and *Get Screened Oakland* (a testing initiative of Oakland, California, Mayor Ronald Dellums), supported by the Levi Strauss Foundation, to provide a forum for stakeholders to discuss freely and openly new strategies for addressing the HIV/AIDS crisis in Miami-Dade. Key stakeholders from the health departments in the state (1), Palm Beach County (1) and Miami-Dade (10), joined federal officials (1), representatives from the office of Congressman Mario Diaz-Balart (1), members of the academy (8), representatives from Dade County Public Schools, (1), community organizations (8) and others (7) in this unique exercise (Appendix A). In facilitated discussions, the group relied on their years of experience battling the epidemic - 20.5 on average - to delve into the complexities of the HIV/AIDS epidemic in Miami-Dade and explore how to solve them.

On Day One, participants worked collaboratively and in small groups to identify policies, procedures, interventions and practices that have worked to reduce transmissions of HIV and/or control the spread of the epidemic and those that have not worked. They compiled exhaustive lists on both sides of the equation that they used on Day Two to develop a set of consensus priorities for the future. The results of their herculean efforts are detailed in the pages that follow.

The HIV/AIDS Epidemic in Miami-Dade

Miami-Dade is located in southeastern Florida. The US Census Bureau estimates that in 2008 the county population was 2,478,585. With the county seat in Miami, the county's population makes up approximately half of the South Florida metropolitan area population. In addition, the county is home to 35 incorporated cities and many unincorporated areas. Non-Hispanic whites comprise only 16% of the population of Miami-Dade where 50.9% of the population consists of foreign-born persons and 67.9% of residents speak a language other than English at home; 15.3% of residents live below the federal poverty line compared to 12.1% of Florida residents overall.



The State of Florida Statewide Coordinated Statement of Need (SCSN) has identified several HIV trends in the state: increases in both males having sex with males (MSM) and heterosexual transmission rates; disparities in HIV/AIDS prevalence associated with race/ethnicity and socioeconomic status; individuals coming into treatment later, resulting in sicker patients; disproportionate impact on MSMs, women, and minorities; and emerging populations that include seniors, migrating populations (farm workers, tourists, aliens) and teenagers. The SCSN notes that the HIV/AIDS epidemic in Florida has shifted to new populations with women, persons of low socioeconomic class, minority populations, the incarcerated and other marginalized groups becoming infected in disproportionate numbers.

The epidemic in Miami-Dade mirrors the state-wide trends. According to its health department, the epidemic is concentrated largely in the northeast section of the metropolitan area (Appendix B). MSM make up the majority reported cases of HIV and of AIDS in 60% of the area's neighborhoods (Appendix C). Following a drop in reported AIDS cases in 2007, the numbers began to rise again in 2008; between 2006 and 2008 the total number of reported HIV infections increased by nearly 30% (Appendix D). Miami-Dade had 584 HIV-exposed newborns in 2007 (Appendix E).

Although Florida law mandates the provision of courses on HIV and sexually transmitted infections (STIs) in public schools, during the 2006-07 academic year, less than one-half of high school students in Miami-Dade were taught pregnancy, HIV, or STI prevention topics in a required health education course. The 2007 Miami-Dade, Florida Youth Risk Behavior Survey, an initiative of the US Centers for Disease Control and Prevention (CDC), indicates that among county high school students:

- 51% have had sexual intercourse;
- 10% had sexual intercourse for the first time before age 13 years;
- 17% had sexual intercourse with four or more persons during their life;
- 37% were currently sexually active (defined as having sexual intercourse within 90 days preceding the survey); and
- 29% did not use a condom during last sexual intercourse (among those defined as sexually active).

Appendix F).



Legislative Recognition of the Epidemic

Medicaid is the nation’s principal safety-net health insurance program financing health and long-term care services for low-income Americans. It is a means-tested entitlement program, jointly financed by the federal and state governments. To qualify for Medicaid benefits, individual must be low-income and “categorically eligible,” *e.g.*, disabled as defined, a parent or a pregnant woman. Being HIV positive does not automatically qualify as a disability. Thus, many people with HIV have trouble meeting eligibility requirements since childless adults who are low-income categorically are excluded from Medicaid (unless they also are disabled or pregnant).

The Ryan White HIV/AIDS Program (Ryan White) is a federal program that provides HIV-related health services. A program for those who do not have sufficient health care coverage or financial resources for coping with HIV disease, Ryan White works with cities, states, and local community-based organizations to provide services. It is administered by the U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau, which awards federal funds to agencies located around the country, which in turn deliver care to eligible individuals under specified funding categories. Comprised of several parts, Ryan White generally is viewed as “the payer of last resort.” To highlight the primary care nature of the program, at least 75 percent of Ryan White funds must be spent on core medical services while the remainder may be spent on support services. Unlike Medicaid, which is an entitlement program, Ryan White is a discretionary program, making services available only as long as funds are available.

Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996. The HIPAA Privacy Rule regulates the use and disclosure of certain information held by "covered entities" (generally, health care clearinghouses, employer-sponsored health plans, health insurers, and medical service providers that engage in certain transactions) and establishes regulations for the use and disclosure of Protected Health Information (PHI). PHI is interpreted rather broadly and includes any part of an individual's medical record or payment history.

In 2006, the CDC officially advised all US providers to test everyone aged 13 to 64 for HIV infection in healthcare settings, and all pregnant women, unless they “opt out” (routine testing). Testing of pregnant women is particularly important because it can lead to prevention of “vertical transmission” of HIV, a situation in which children are infected with HIV during gestation, during



delivery or through breast-feeding. Because there are a number of available interventions to prevent such mother-to-child transmission, the earlier the diagnosis of HIV infection in pregnant women the greater the opportunity to avoid infection in their children.

Florida was among the first states in the nation to adopt comprehensive AIDS legislation when it adopted the Omnibus AIDS Act in 1988. The Omnibus AIDS Act of 1988 (Omnibus Act) contains a number of key requirements, including:

- training of all health professionals tailored to their professions;
- testing for HIV, and delivering results, that is informed, voluntary, and confidential;
- notifying individuals of their right to anonymous testing;
- documenting consent to testing;
- delivering post-test results in person and, if results are positive, providing information about social and health care services;
- providing for authorized release of information to a third party.

The legislature amended the Omnibus Act in 1996 to require all physicians and laboratories to report HIV positive tests results to state health authorities and to require all health care providers of pregnant women to offer HIV testing as a routine blood test. The 1998 amendments to the Omnibus Act eliminate pre-test counseling requirements, allow for repeated testing without further consent (to monitor treatment and progress of the disease, after consent for an initial test), limit post-test counseling requirement to the local health departments and registered HIV testing sites, and require health providers to make reasonable efforts to notify individuals of test results. Except in situations where specifically defined, “informed consent” to perform an HIV test in Florida need not be written so long as it is documented in the medical record.* Minors generally may request an HIV test without parental consent.

Florida law requires that all providers attending a pregnant woman to offer her the option for HIV antibody testing.** In addition, Florida law requires biennial completion of a health-department-approved educational course on HIV, including “information on current Florida law on acquired

* Fla. Admin. Code § 64D-2.004.

** § 384.31 Fla. Stat. (2008).



immune deficiency syndrome and its impact on testing, confidentiality of test results, and treatment of patients” as a condition of professional relicensure” for midwives, optometrists and others - but for not physicians.*

Through the Looking Glass

Over the course of the two days, the participants sought to hold a mirror up to the HIV/AIDS epidemic and envision a world on the other side of that mirror. They were able to reach consensus on a goal toward which HIV/AIDS efforts in Miami-Dade should be directed: reducing transmission of HIV. That goal, however, is multi-factorial in nature. The participants agreed that reducing transmission of HIV must be accomplished through a sub-population by sub-population approach. In defining the ultimate goal, the participants discussed a number of impediments to reaching it (Appendix G).

Infrastructure Challenges

The participants identified various infrastructure challenges that must be resolved if HIV transmission rates are to be reduced in Miami-Dade. Primary among the challenges identified is the lack of a single mechanism to pay for HIV/AIDS care and treatment. There was general agreement by those present that our fragmented system of care is not working on multiple levels. They said:

What doesn't work is the Ryan White Programs . . . the fragmentation of the system itself. So at the local level the patients that need services will have to go through four or five, six different agencies in order to get access to the different services that are available. And that's part of the problem [Javier Romero, Director, AIDS Service Programs, Miami-Dade Department of Health].

As a consumer living with HIV, I'm going to echo one of the comments made about, in terms of Ryan White. But I think it's more than Ryan White as far as something that needs work. It's the whole continuum of care, the access to care and service. I'm

* §381.0034 Fla. Stat. (2008).



Medicare, I don't want to use ADAP because I don't want to use the State Department, the State Health Department Pharmacy, but I don't have the six thousand for my Medicare co-pay at the same time. So I'm on holiday. . . So I think that, you know, our systems aren't linked and aren't as efficient as they could be, I think, to give people the confidence to get testing to find out their status. . . But at the same time some people don't understand the funding streams. They don't understand the dollars are actually coming from the federal government through the Ryan White Program. So, you know, their lack of education or lack of knowledge on the systems that are funding them. [Michael Rajner, Community Activists/Organizer].

Medicare Part D and Medicaid, we're talking about this, have substantive formulary problems. They're treating patients as if one shoe fits all. I'll give an example with anti-lipid lowering agents. You know, we have to be very restrictive as to what patients we use in terms of certain medications [Michael Kobler, MD, Jackson Memorial Hospital, University of Miami].

But in reality, if we're talking about stigmatization, having a separate system of care like the Ryan White Care Act for a segment of the HIV infected population also still continues to stigmatize in a very different kind of way. But it's still there [Christopher Bates, Observer].

Federally Qualified Health Centers* came under particular scrutiny from the participants. No one in the room disagreed with Marlene Lalota, Prevention Director, Bureau of HIV/AIDS, Florida Department of Health, when she stated that “they’re the only ones getting any money. . . They got

* A Federally Qualified Health Center (FQHC) is a reimbursement designation referring to several health programs funded under the Health Center Consolidation Act (Section 330 of the Public Health Service Act) and includes Community Health Centers which serve a variety of federally designated Medically Underserved Area/Populations.



tons and tons of money. Where are they in this fight.” Nor did anyone disagree with Ms. Ullah when she said, “My federally qualified health centers, I’m sorry, it’s a failing grade.”

Ralph DiClemente, MD, of Emory University noted a particular infrastructure challenge that needs to be addressed. Martina Devarona, Miami-Dade Department of Health, and Steven Bowen, MD, Nova Southeastern University, joined Dr. DiClemente in his view that behavioral change programs work to reduce transmission. But, Dr. DiClemente noted, there is no infrastructure by which to transfer those programs into community practice. Similarly, Ms. Ullah noted the absence of any infrastructure to transfer academic research into usable products at the community level.

Although Florida law mandates HIV education for public school students, the school system came under scrutiny by the participants. As for the rising epidemic among teenagers, Jacqueline White of the Dade County Public School System noted that

“It’s [HIV component to health education curriculum] mandated in our district, kindergarten through twelve grade, that students will receive five hours annually of AIDS education. It’s a board rule.”

“I want to address a tremendous disconnect in the education. The state of Florida two years ago eliminated health education as a required course for graduation. [N]ot only have they eliminated it as a required course for graduation, they’ve taken out all the human growth and development standards and benchmarks out of the health education standards. . .So even though our district has a mandate that we teach it, we are trying to figure out where.”

Finally, Marsha Martin, DSW, *Get Screened Oakland*, noted an especially broad infrastructure challenge that intersects with the many specific challenges mentioned: The lack of federal funding “to sociologically address HIV, to culturally address HIV, [and] to politically and economically address HIV.”



Personnel and Operational Challenges

Changes to infrastructure alone will not solve all of the problems, according to the participants. Unfortunately, many participants noted the failure of physicians to engage in routine testing as a potent impediment to curbing transmission rates. They expressed the view that while community-based organizations and health departments are doing outreach and testing, private providers continue to harbor a number of misconceptions about their obligations to perform routine testing. For example, Marlene Lalota noted,

People in the private sector continue to believe that the laws are very onerous and that they're more complicated than they really are, despite ten years of efforts of educating. There's no pretest counseling required. There's no post-test. Consent doesn't have to be in writing. People refuse to give up those things. Hospitals and clinics will not give up their written consent forms.

Anna Garcia of the University of Miami supported that view when she stated, “But at least in our community we know that the private sector [providers] sometimes get off the hook and don't feel it's their responsibility because they have all these specialists and community centers that do the work.” And, Donna Futterman, MD, of the Albert Einstein Medical Center in the Bronx, New York, echoed their sentiments with her observations that “there is a small AIDS world that's very dedicated. The doctors are mission driven. The nurses are all right there. The social workers, I mean we have an amazing community of HIV providers. But what we haven't been effective at is having any kind of authority to move the rest of the doctors into doing it.” On the other hand, Dr. Bowen gave the example of the North Broward Hospital District Primary Care facility where physicians simply did not offer routine HIV testing despite a written policy that it is to be offered and strongly recommended “by every physician, every primary care visit.” Hector Bolivar of the University of Miami attributed this failure on the part of primary and young physicians to a lack of education.

The “silo” mode of operation was a prominent theme among the participants. Kalenthia Nunnally-Bain, Teen Pregnancy, Inc., stated the issue quite succinctly when asked what was not working and she replied, “Silos. That would be it.” Ketty Ledan, Miami-Dade Department of Health, is encouraged by the number of programs in the county but noted a lack of understanding between programs of their various operations. Hudes Desrameaux of Care Resources, Inc., expanded the



silo theme with his comment that, “[w]hat’s not working, I believe, is bringing to the table key community groups like the church and like the businesses, and non-HIV organizations to address the HIV epidemic. That’s not working.” Lorenzo Robertson, Palm Beach County Department of Health, offered his views in support when he noted that HIV organizations do well communicating with each other but fail to reach out “to the other parts of the community” such as the Urban League and the NAACP.

There was uniform agreement among the participants that antiretroviral therapy works. The challenge, they see, is keeping patients in treatment. Linking patients to care, particularly scheduling appointments and ensuring they are kept, pose special challenges in the eyes of the participants.

Meeting the Challenges

The participants came together on Day Two to develop a plan for meeting the challenges they had identified. They worked in two groups to address four tools for reducing HIV transmission: Reaching, Screening, Linking and Serving. Each group was tasked with developing an action list for reaching more citizens, screening them, linking them to care and continuing to serve them. The complete lists of action items developed by the groups are contained in Appendix H while some of their more salient points are detailed below.

Reaching Group 1

Well, instead of just going into the pockets where they need testing, we need to go a little further. We have to go out to the outline. We don't want to stigmatize that area and say, you know, we're just going to go into, I mean, let's be realistic, we don't want to just go to Liberty City or areas where we think. No, we need to come back out of it and maybe come back in. Start out maybe in the downtown area and then work ourselves out where we could then extend ourselves out. There's two areas that we have to target, the health industry and then also public partners outside of the medical community. There [are] other organizations that are involved. Maybe we need to do a city-wide initiative. Miami-Dade city-wide



initiative where everyone is included. Have the mayor support it just like they did in Oakland.

Group 2

We thought that there was a lot of power with the faith-based providers. That there are a lot of residents in our communities who respect and appreciate the word of these leaders. And that would be a good way to get people possibly to get tested because they're listening to what the pastor is saying about getting tested.

Screening

Group 1

[T]arget . . . the private hospitals, not just Jackson. Where we can go into the Baptist Health System. Or we can go into the Catholic, Mount Sinai, Mercy. And we can't forget them. . . maybe we need to change the message for screening. Regarding to STDs, regarding going into the jails, the emergency rooms, community health centers, labor and delivery, communities of color, or the gay community. Going into nightclubs, not just some nightclubs but all nightclubs in all the hotels.

Group 2

So screening, buy-in by the key stakeholders. How do we get people to buy into screening our residents? We want the doctors to be accountable, the ones in the private sectors. We want them to take more responsibility of these private providers. . . in our community we know that the private sector [physicians] sometimes get off the hook and don't feel it's their responsibility because they have all these specialists and community centers that do the work.



Linking Group 1

Instead of providing money for counseling and testing and providing money for linkage to care, you know, putting that money together where it's just one, you test and you have better linkage to care, it's all one. And a one-stop model, which we've had those before. And they've worked.

Group 2

Linking, we want to break the barriers to sharing the information, such as sometimes HIPAA imposes. We have barriers getting into care, insurance barriers, no insurance. Medicaid, one day you have an HMO that allows you to see one provider, and 30 days later you have another HMO that your provider doesn't accept. And so you have this interruption of care.

[I]nadequate case management. There's a lot of consensus with my colleagues here today that the case management system in metro Dade County is broken. It needs a serious revamping and it itself is a barrier to care.

Serving Group 1

[We would] consider maybe having a retention coordinator versus a linkage to care person.

Group 2

[B]est practices, prevention for positives. We wanted to encourage HIV infected individuals to have their partners tests or their friends, if they're not acknowledging that it's a partner. And to promote adherence to medications and appointments.



We want to engage schools of nursing, public health, social work, medical, law students and maybe consider a multi-disciplinary team approach to do this work for us.

Toward a Vision of Thoughtful Change, Miami: Action Items

At the conclusion of Day Two, the participants reached consensus on a number of action items. They are as follows:

Reaching

1. Play nice / play together
2. Use surveillance data strategically by zip code
3. Launch city-wide collaborative initiative

Ms. Ullah: The main target communities are: Little Havana, Little Haiti, Liberty City, South Beach and Miami.
4. Reach institutional leadership and structure a system
5. Conduct outreach with more mobile units for testing
6. Remind people that HIV is a priority and educate them over and over
7. Make the case for HIV as a public health issue
8. Select proper venues
9. Engage in community mobilization and outreach



Screening

1. Shift the message from the risk group
2. Give health providers the responsibility and accountability for HIV screening
3. Engage leadership at all levels
4. Change laws and CDC regulatory policies

Linking

1. Engage local institutions in city-wide initiatives
2. Eliminate duplication of services results from inadequate software systems
3. Coordinate networking / agency communication
4. Build and strengthen the prevention and early intervention services
5. Identify other potential services HIV patients need

Serving

1. Promote prevention for positives including adherence and compliance
2. Remove barriers to accessing substance abuse services
3. Insure standards of care and practice development in Miami-Dade
4. Issue a report card on servicing people with HIV (enforce guidelines)

Next Steps

The Think Tank will reconvene to develop an implementation plan based on the above action items.

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A THINK TANK EXPERIENCE
MAY 4, 2009

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COMMISSIONED BY
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Submitted by:
S&H Consulting, LLC
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May 15, 2009



Implementing the Action Items

On June 25, 2009, the Miami-Dade County (Miami-Dade) Health Department, Office of HIV/AIDS (The Office), will launch a countywide HIV testing initiative, *Test Miami*. Preparatory to that launch, Evelyn Ullah, BSN, MSW, Director of The Office, convened a meeting of its staff and strategic partners from both public and private sectors on May 4, 2009. At that meeting, attendees reviewed the recommendations and action items developed during the Think Tank, *Toward A Vision of Thoughtful Change*, on February 18, 2009.

As before, attendees worked in small groups to arrive at consensus on an implementation plan for Miami-Dade's HIV testing initiative. The implementation plan, that follows below, is divided by area of responsibility for The Office, its community partners and local health care providers.



Government - Tasks	Deadline
<p>Secure letters from Mayor Manny Diaz to highlight the work being done in Oakland, Bronx and Los Angeles and noting local surveillance data and a “minimal cost” statement:</p> <ol style="list-style-type: none"> 1) All mayors/commissioners of highly impacted areas announcing Test Miami initiative 2) Congresspersons Balart, Ros-Lehtinen, Meeks 	<p>May 15, 2009</p> <p>May 25, 2009</p>
<p>Create a database of partners’ testing statistics and routine testing implementation processes to track and document <i>Test Miami</i> success</p>	<p>ASAP</p>
<p>Secure letters of support from MDCFAR partners</p>	<p>June 15, 2009</p>
<p>Engage in outreach with:</p> <ol style="list-style-type: none"> 1) Elected officials, to obtain buy-in 2) <i>Save Dade</i>, as a collaborating partner 3) Media (including celebrity spokesperson Charles Perez; health writer Diana Gonzales) 4) First responders (police and fire departments, etc.) 	<p>June 15, 2009</p> <p>May 15, 2009</p> <p>June 15, 2009</p> <p>June 15, 2009</p>



Community Partners - Tasks	Deadline
Send letters to identified AIDS service organizations and agency partners to participate in a May 21 meeting at City Hall	ASAP
Engage in outreach among Part A agency representatives to attend the May 21 meeting and to support and attend <i>Test Miami</i> launch on June 25	ASAP
Launch soft media campaign in support of <i>Test Miami</i>	June 19, 2009
Organize health and testing fair as part of the <i>Test Miami</i> launch and photo opportunity (with Mayor Manny Diaz, testing vans, local providers/AIDS service organizations)	June 19, 2009



Hospital & Clinics - Tasks	Deadline
Secure buy-in from high level leaders (CEOs, presidents, medical directors, <i>etc.</i>) of major health care institutions including hospitals and clinics/clinic networks	May 15, 2009
Convene first workshop of partner hospitals and clinics to facilitate development of institutional routine testing implementation plans*	TBA and ongoing
Work with AIDS Education and Training Center(s) to improve prenatal testing to focus on achievement of uniform third trimester testing	TBA
Prepare talking points to "sell" routine testing to health care institutions: medical rationale, business case, community involvement, etc.	ASAP
Compile surveillance data on HIV testing among partners, including: number patients seen; number of HIV tests conducted; and number of positive tests received (establish baseline and track ongoing after launch)	ASAP

* An area of particular concern raised by attendees is the apparent failure of physicians to offer HIV testing to pregnant women during the third trimester of pregnancy notwithstanding the requirement of Fla. Admin. Code § 64D-3.042 that such tests be offered “[a]t initial examination related to her current pregnancy; and again at 28 to 32 weeks gestation.”