NATIONAL WOMEN AND AIDS COLLECTIVE

INTERIM REPORT TO THE JOHN M. LLOYD FOUNDATION:

***THE MODEL CITY: A STRATEGY FOR A MORE COMPREHENSIVE AND EFFECTIVE HIV SURVEILLANCE SYSTEM FOR WOMEN AND OTHER VULNERABLE POPULATIONS* (MAY 14-16, 2010)**

Question 1: Were the conference goals achieved?

Yes. The National Women and AIDS Collective (NWAC) proposed to convene community-based advocates, local and state AIDS policy directors, and selected federal agencies to explore the adoption of HIV surveillance systems that incorporate social determinants for more inclusive and effective prevention and treatment services. Because of the meeting:

- NWAC members enhanced their understanding of the current surveillance system and its limitations, as well as promising state and local models that supplement the system with data addressing the social determinants of health. A key presentation at the convening led NWAC to reconsider the target level (i.e. federal versus state) at which it seeks to bring about change (see *Clarifying the Model City* below);
- State and local surveillance personnel learned that some state counseling, testing, and referral (CTR) programs still turn away women as "low risk" and test only individuals from a pre-determined target population, and others prefer to test men because of fee disincentives that provide a lower reimbursement rate for women. These points were key in helping advocates to identify gaps and/or inconsistencies in disparate implementation scenarios of HIV surveillance;
- Participants agreed on the value of innovative supplemental surveillance models that consider structural (socioeconomic) factors and take advantage of state and local flexibility, while working for refinements of the surveillance system that appear feasible in the short term; and
- Key participants – within and outside of NWAC– recognized the unique role that NWAC can play in advocating for models of surveillance that collect supplemental data other than risk-based data.

Our proposed goal for the conference, stated above, stems from a multiyear strategic plan to map specific policy demands that incorporate social determinants in order to more fully identify women's exposure to HIV. This convening afforded us the opportunity to review and discuss progress, plans and roadblocks with our allies and assess various processes for collecting key socioeconomic factors at the root of this work, particularly affecting women of color and low-income women. Bringing our allies to the table face-to-face further allowed us to progress in formalizing our partnership/relationship with local health jurisdictions.

NWAC did not, however, leave the conference with a concrete work plan, as we had originally proposed. Originally, it was expected that the meeting would include action planning for implementation of our model for change in at least one jurisdiction but the agenda was revised based on information obtained through the expert presentations. NWAC leadership met immediately after the Sunday morning session, to discuss implications and next steps: as a result, the NWAC Leadership Team met in June 2010 and will meet again in August 2010 to further solidify the details of the plan going forward as well as an accountability structure to keep this work progressing as NWAC transitions over the coming months and year. (See *NWAC Transition and Structure* below.)

Question 2: Who attended the conference?

This convening brought together 24 NWAC members, surveillance and other health department staff, social scientists, and grantmaker personnel.

First	Last	Organization	Conference Role
Emily	Gantz McKay	Mosaica	Evaluator
Colin	Flynn	Maryland Department of Health and Mental Health	Expert in the field
Dr. Carla	Lewis	Children's Health Fund	Expert in the field
Ellen	Weiss Wiewel	New York City Department of Health and Mental Hygiene	Expert in the field
Makani	Themba-Nixon	The Praxis Project	Facilitator
Faith	Mitchell	Grantmakers in Health	Funder
Patricia	Eng	Ms. Foundation for Women	Funder/Co-sponsor of meeting/Vice President
Desiree	Flores	Ms. Foundation for Women	Funder/Co-sponsor of meeting/ Program Officer
Melanie	Havelin	John M. Lloyd Foundation	Funder/Co-sponsor of meeting/ Executive Director
Brenna	Lynch	Ms. Foundation for Women	Funder/Co-sponsor of meeting/Program Associate
Carrie	Broadus	Women Alive	NWAC Leadership Team
Liz	Brosnan	Christie's Place	NWAC Leadership Team
Vanessa	Johnson	National Association of People with AIDS	NWAC Leadership Team
Naina	Khanna	Women Organized to Respond to Life-Threatening Diseases/U.S. Positive Women's Network	NWAC Leadership Team
Sylvia	Lopez	Women Rising	NWAC Leadership Team
Jo	Schneiderman	Twin States Network	NWAC Leadership Team
Clarissa	Silva	SMART University	NWAC Leadership Team
Rona	Taylor	National Women and AIDS Collective	NWAC Organizer
Zina	Age	Aniz, Inc.	NWAC Member
Sharon	Day	Indigenous People's Taskforce	NWAC Member
Valorie	Eckert	California Department of Public Health	Research Scientist
Nkechi	Oguagha	New York State Department of Health	Director of Special Populations
Eve	Mokotoff	Michigan Department of Community Health	Expert in the Field
Kasia	Gladki	Ms. Foundation for Women	Videographer

Question 3: Please attach any pertinent conference materials
Please see attached Conference Agenda and Pre- and Post-Conference Evaluation Surveys.

Question 4: What unanticipated issues/challenges/successes were raised at the conference? And how do you plan to follow up on them?

Challenges:

Clarifying the Model City

Perhaps the most significant and consequential challenge of the meeting was participants' realization and identification of shortcomings in NWAC's "model city." One NWAC member expressed disappointment over "confusion around what we were referencing by the term 'model'" as it was used to refer to both a "model city" instrument as well as a "model for change" overall strategy. Surveillance personnel and social scientists mentioned the lack of clarity and need for revision of the NWAC model for change (which NWAC members decided to refine based on information gained at the meeting), as well as the need for "more transparency" around the model.

The "model for change" is an analysis of the type of global change that needs to happen to ensure optimal surveillance outcomes for women. This includes changing implementation of practices around HIV testing, eliminating a tiered fee structure that creates a disincentive around testing women and the inclusion of social determinants in order to provide a context for women's lives. In addition to the clarity around what the "model for change" is, presenter Eve Mokotoff recommended that NWAC consider switching its strategy from a federal level strategy to a state level strategy. This was echoed by the facilitator.

The "model city" on the other hand, is still very conceptual and the meeting provided NWAC with the building blocks or components of what a model city could be. In other words, a model city would be one that utilizes the bottom up approach of the DPM (see below) to ensure a population prioritization and resource allocation process that is community driven, inclusive and fair, in addition to a testing methodology that eliminates a high risk behavior paradigm.

One of the core successes of the meeting was learning what pieces of a feasible methodology for a model city look like. These best practices include:

- *Dynamic Prioritization Model* (DPM)
  This "bottom up" approach will be a useful "tool" for NWAC's base to organize at the local level since it was designed specifically for community planning through involvement in the local Prevention Planning Group and/or Ryan White Planning Council. NWAC would like to tie this model to funding with the idea that all populations will receive money based on what the epidemic looks like in their community. Most often, when community planning is done the only variable that was considered was the prevalence (number of people living with HIV/AIDS). The DPM, on the other hand is inclusive of the prevalence, all racial groups, ages, races and sexual orientations and weights several social co-factors which provides more contextual information and demonstrates that a health jurisdiction can incorporate social determinants into its community planning and is flexible enough to incorporate social determinants such as

poverty, substance abuse, homelessness, domestic violence, incarceration, and does not require developing new instruments.

- *Social Determinants in HIV Surveillance Data*
  Another suggestion was to utilize behavioral surveillance data that is inclusive of social determinants and GIS mapping (practiced by the Maryland Department of Health and Mental Hygiene and many other jurisdictions across the country funded by the CDC to do targeted testing) to ensure identification of higher rates of heterosexual individuals that are HIV positive. This strategy does away with a risk based paradigm and uses the GIS mapping to identify where the highest prevalence (numbers of people living with HIV/AIDS) are located. This methodology showed that using a targeted testing method which utilizes geography versus a targeted testing method based solely on risk (the current CDC practice at counseling, testing and referral providers in community based settings)resulted in approximately a 2% increase in the number of heterosexual individuals which were able to be tested and diagnosed. Currently, this approach is primarily a "pilot" in certain jurisdictions.

- *Consistent Definition for "risk"*
  One of the key issues around high risk heterosexual definitions is that they are inconsistent across all the different types of surveillance that the CDC uses. One definition offered at the Lloyd conference as a consistent definition is the definition that is currently part of the routine testing guidelines, which is anyone that is sexually active and living in a high prevalence area should be tested.

To follow up, NWAC will incorporate these insights as a core part of its planning process in the August 2010 meeting.

Refining Policy Recommendations
One issue that represents both a success and a challenge is in regard to the CDC's recommendations for routine testing of adults and adolescents in health care settings. One of the points that was raised by a guest presenter was that out of all the people who were tested approximately 20-25% of testing is conducted in community based organizations with the other 80% of testing occurring in medical settings such as emergency rooms, community health care centers and private doctor's offices. Although, this information may have been a surprise to some, it does not ring true in every health jurisdiction in NWAC's network. For example, in Vermont recent statistics reveal that 76% of testing and counseling happens in community based counseling, testing and referral sites. And in Texas, officials at the state health department could not confirm the relative proportions of HIV tests in various settings so it is difficult to know whether this 80%-20% relationship rings true.

Although there may be consistent policies, interpretation of "how to implement/apply these policies is left to the local jurisdiction. Thus, HIV testing guidelines that have been in effect for several years are being "lost in translation." Additionally, in some health jurisdictions where NWAC members are located a tiered reimbursement system exists, which incentivizes providers to test those who are perceived higher risk versus low risk -- namely - women, Asian Pacific Islanders and Native American populations. This part of the dialogue underscores the need for the paradigm shift that NWAC envisions in order to engage women to get the HIV test and if they are HIV-positive, then they should be linked to care before they progress to full blown

AIDS. According to the CDC, "in an analysis of several studies involving more than 4,500 people with HIV infection, women were 33% more likely than men to die within the study period. The investigators could not definitively identify the reasons for excessive mortality rates among women in this study, but they speculated that poorer access to or use of health care resources among HIV-infected women as compared to men, domestic violence, homelessness, and lack of social supports may have been important factors."[1] This distinction is critical to NWAC's work because if women were tested sooner then they would live longer; domestic violence, homelessness and lack of social supports are exactly the types of information that NWAC would like to see captured in terms of social determinants. These social determinants form a context for women's lives.

Attendance

Due to circumstances beyond NWAC's control, such as state budgetary constraints, competing priorities and family illness, **key participants** from the National Association of State AIDS and Territorial Directors (NASTAD) and the Centers for Disease Control (CDC) **were not able to attend**. With short notice, there was not enough time to invite others and this had an impact on the agenda and the dynamics of the meeting. The agenda that had been carefully planned for several months changed as a result and the facilitator and the Leadership Team did not have a real opportunity to solidify all of its elements.

To rectify this situation as best as possible, NWAC plans to disseminate conference reports and external documents to these key personnel to keep them engaged in NWAC's work and informed of progress.

Conference Facilitation

Many participants felt that the facilitator's style was not effective in ensuring that NWAC maximized the opportunities at hand. A post-survey of the conference reveals that the Agenda and Flow were rated as the weakest aspect of the meeting (2.9 out of 4; see attached post-survey). Some participants felt that there were missed opportunities for the group to go deeper and identify next steps with the allies in the room. Unfortunately, the facilitator did not allow this type of engagement for the participants and neither NWAC nor the Ms. Foundation staff in attendance interjected to modify the course of discussions.

To avoid this in the future, more time will be spent in the preplanning stage with the facilitator, NWAC and the Ms. Foundation staff to ensure that the our meeting objectives take priority. Also, more time will be allocated to debrief after each meeting/session.

Conference Success

Seven of the nine NWAC members in attendance felt that the most useful part of the meeting was the presentations by state and local health department representatives and social scientists. Thanks to the strong content of the meeting, NWAC is positioned to continue to "move the ball down the field" because conference presentations and best practices shared provided the building blocks for our model city concept to support a fundamental paradigm shift that moves away from a framework based on "*high risk behavior"* to one based on prevalence and social determinants. A paradigm shift based on "social epidemiology" will address the "stressors" (e.g., racism, poverty, gender oppression, etc.) that place populations, particularly women at risk of HIV and the characteristics that enhance their

[1] "HIV infection in women," NAIAD, May 2004, http://www.niaid.nih.gov/factsheets/womenhiv.htm.

vulnerability to acquiring HIV. This is because mortality based surveillance does not account for "how" social determinants (e.g., economic and political) perpetuate inequalities in HIV/AIDS, and the "how" we address changing the structure of the social environment to help empower vulnerable populations to decrease their risk of exposure to HIV/AIDS.

Question 5: Were any conference proceedings or papers generated as a result of the conference? If yes, how will they be distributed and to whom?
Although NWAC intends to compose papers for distribution to the AIDS surveillance and prevention community, they have not yet been generated. They will be distributed to those unable to attend the meeting, as well as key stakeholders and advocates in this field.

Question 6: What are the next steps?
Immediately after the meeting the Leadership Team met along with staff of the Ms. Foundation and NWAC network members to debrief and evaluate progress.

As laid out in our proposal, with the additional $20,000 from the John M. Lloyd Foundation, NWAC will build on the learnings of the conference by continuing – and, where necessary, modifying – its policy and advocacy work in support of the development and use of inclusive surveillance models, including collaborating with local, state, and national policy makers and legislators and working with researchers such as the CSTE and the CDC on revisions to the national surveillance system (including staff time, conference calls and travel as necessary). NWAC will also assist community planning bodies, service providers and other stakeholders to further understand the use of social determinants through a series of widely-available regional and national webinars that would include the presentation of research, NWAC's policy platform for revision of the federal surveillance system, and case studies of current projects that are incorporating social determinant data.

In addition, your support will enable us to learn from this convening experience through rigorous evaluation. As laid out in our proposal, the Ms. Foundation's external evaluation consultant, Mosaica, will analyze and write up the evaluation survey results (Note: evaluation was built into the meeting with a representative from Mosaica in attendance. They designed and implemented the attached pre and post surveys, analyzed results, and are drafting a document for external circulation. Therefore, a portion of the $20,000 yet to be received from the John M. Lloyd Foundation has already been partially expended.)

Mosaica's analysis will enable us to assess progress on the following convening goals:

- participants understanding of the national HIV surveillance system currently in use, and its implications for prevention and treatment resource allocation and for identifying emerging at-risk and affected populations;
- participants understanding of social determinants and the potential benefits of using social determinants for more accurate and predictive service delivery; and
- participants' development of formal and informal collaborations to explore the use of social determinants in their work, and craft a group work plan for continuing to develop, advocate for and implement models incorporating social determinants.

Immediate Next Steps:
NWAC, with the support of the Ms. Foundation for Women where needed, is accountable for the below workplan, to be more fully planned at the August 2010 meeting.

1. Create NWAC 2010 position paper on our "Making Women a Priority Population" logic model as background, first. Determine what elements we need regarding the landscape and best practices, set a timeline and start the work.
2. Review our recommendations and incorporate feedback (or not).
3. Begin to develop NWAC's concept of a model city based on the best practices collected.
4. Develop a toolkit and talking points on the recommendations that should be very helpful in engaging other people such as NWAC's network, health departments and the CDC. Include mission and vision.
5. Once the information is synthesized, then have a conference call with the leadership team. Have NWAC member organizations that were represented at the meeting participate in the call. Their input will be critical in providing NWAC with guidance about what it is that they would need to move the work around surveillance and social determinants forward.
6. Adopt the practice by Maryland Department of Health and Mental Hygiene to utilize census level data on social determinants and GIS mapping methodologies; adopt the proposition made during the meeting to go beyond the female presumed heterosexual category to just a heterosexual category.
7. Follow up with Eve Mokotoff and Colin Flynn from the meeting and discuss steps for moving forward together.

Progress
As of July 2010, the Leadership Team (LT) has had one call to talk about its position paper and a framework has been developed. The LT is in the process of determining what further information is needed, if any, to finish writing the paper and is laying plans to complete it.

Subsequent LT calls will be devoted to updates around the position paper, work on the power analysis and toolkit and the formalizing of NWAC's structure.

NWAC Transition and Structure
The LT is committed to assisting the Ms. Foundation in fulfilling the terms and responsibilities (including deliverables) as specified in the John Lloyd Foundation grant award. The grant award provided NWAC with a wonderful opportunity to bring together a variety of representatives from health departments, community based organizations and advocates to assist the group in determining its next steps as it pursues its advocacy campaign to change the national HIV surveillance system. This change is necessary if we, as a nation, are to best meet the HIV prevention needs of women living in the United States.

As has already been done, in other sections of the document, the successes and challenges associated with this convening have been explored and explained. Yet, what has not been explained is the impact that the convening had on the NWAC LT. Despite what may or may not have been achieved, the LT believes that it is ultimately responsible for the successes and challenges arising out of the convening and will use the lessons learned from this experience to spring forth into a new beginning.
Several action items have been taken in this regard:

1. NWAC will now be a separate entity from the Ms. Foundation. In June 2010, Ms. Foundation and NWAC met to work out next steps toward NWAC's independence. Over the next several

months, NWAC will take several steps, including entering into an agreement with one of its sister agencies, Twin States Network, located in Vermont to serve as its fiscal agent. The Ms. Foundation will provide a planning grant and continue to provide in-kind assistance, including office space, phone, copying, etc. along with identified staff support. The NWAC organizer will transition to a consultative role in this interim period while the structure and leadership of NWAC is being finalized.

2. NWAC has engaged the services of an organizational development specialist who will serve as its facilitator over three important planning meetings. These meetings are scheduled for August 2010, November 2010 and January 2011. The purpose of these meetings is to engage in a strategic planning process. The NWAC LT has determined that this is necessary if it is going to address some of the short comings that happened at the John Lloyd Foundation convening. For example, NWAC has a decision making structure but what the John Lloyd Foundation convening uncovered is that the NWAC LT needs to improve how the its members communicate with one another, how it communicates with individuals working on its behalf, how it communicates with other NWAC member organizations, and how it communicates with the community-at-large. If NWAC is going to be successful with its national capacity building efforts and its efforts to change policy then it must begin to work at a level which demands clear and decisive thinking and decision making. Its current structure as a diffused network of committees may not be the most appropriate structure to do this.

   The August 2010 strategic planning session will also incorporate the development of a work plan and timeline for completion of items due to the John Lloyd Foundation. For this purpose the organizational development specialist will also serve as the LT's coach to ensure successful project management.

The NWAC LT believes that the aforementioned steps will work towards ensuring that the outcome of future meetings of this nature will be far more satisfactory to everyone involved.

Conclusion
The Ms. Foundation for Women and the National Women and AIDS Collective are grateful to the John M. Lloyd Foundation for their financial and technical support through this grant. We look forward to continuing our work with you.