FIMR/HIV PREVENTION METHODOLOGY

Request for Applications: Deadline August 28, 2009

The goal of the FIMR/HIV Prevention Methodology is to improve perinatal HIV prevention systems by using the FIMR case review and community action process.

This RFA seeks new communities interested in implementing the FIMR/HIV Prevention Methodology as part of a national practice community, requiring a commitment of 12 months (October 2009 - September 2010). To be eligible, communities must have the ability to identify and review 25-35 cases of mother-to-infant HIV exposure per year.

*Technical assistance (teleconferences, sites visits and in-person training) from the American College of Obstetricians and Gynecologists (ACOG), National Fetal and Infant Mortality Review (NFIMR) Program, City**M**at**CH** and the Centers for Disease Control and Prevention (CDC) will be made available to sites implementing the FIMR/HIV Prevention Methodology. Additionally, sites will have access to resources on the City**M**at**CH** website.*

Communities may apply for participation with funding or participation without funding. Selection of funded sites (anticipated award level of $22,500) will be determined based on demonstrated need and efficient use of all program funds and resources.

PROJECT BACKGROUND

There has been a remarkable decline in perinatal HIV transmission (also known as mother-to-child transmission of HIV) in recent years. However, the CDC reports, "Between 120,000 to 160,000 women of childbearing age in the United States are infected with HIV, the virus that causes AIDS. Nearly one out of four of these women don't know they have HIV. This puts them at high risk of passing the virus to their babies."[1] This reality highlights the importance of continuing to strengthen perinatal HIV prevention efforts. Many cases of perinatal HIV infection "involve women who were not tested early enough in pregnancy or who did not receive prevention services."[2]

In October of 2005, City**M**at**CH** and the American College of Obstetricians and Gynecologists, including the National Fetal and Infant Mortality Review (NFIMR) Program, were funded by the Centers for

[1] Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. *Pregnancy and Childbirth*. Available at: http://www.cdc.gov/hiv/topics/perinatal/index.htm. Accessed December 10, 2008.

[2] Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention, HIV/AIDS Fact Sheet. Mother-to-Child (Perinatal) HIV Transmission and Prevention. Available at http://www.cdc.gov/hiv/topics/perinatal/resources/factsheets/perinatal.htm. Accessed April 7, 2009.

Disease Control and Prevention's (CDC) National Center for HIV, STD, and TB Prevention (NCHSTP) to adapt a sentinel health event methodology for the investigation of perinatal HIV transmission[3]. The overall goal of the work was ***to adapt the Fetal and Infant Mortality Review (FIMR) process in order to identify and address missed opportunities for perinatal HIV prevention and treatment in pilot sites.***

Three pilot sites (Baton Rouge, Louisiana; Detroit, Michigan; and Jacksonville, Florida) were selected to implement the FIMR/HIV prevention methodology over the course of two years. These sites were responsible for locating and engaging community members with expertise in HIV/AIDS and maternal and child health (MCH) to review data (i.e., from medical records and maternal interviews) in order to make recommendations for community action and systems changes needed for optimal perinatal HIV prevention. City**M**at**CH**, ACOG, and NFIMR provided technical assistance and startup funds for the pilot sites. Each community's efforts resulted in improvements to systems serving women with HIV infection and their families. The lessons learned from these communities are documented in the final report *FIMR/HIV Pilot Project: Overview and Lessons Learned,* to be released in July 2009 (available at www.citymatch.org).

SUMMARY OF THE METHODOLOGY

The FIMR/HIV Prevention Methodology is based on the premise that the pregnancy experiences of women with HIV infection are sentinel events that warrant review to inform interventions that will improve systems of care for the mother and infant. By collecting comprehensive quantitative and qualitative data, via medical record abstraction and maternal interview, the methodology provides an in-depth look at the systems that result in a perinatal HIV exposure or transmission. This examination allows communities to identify system strengths, missed opportunities for prevention and, more rarely, failures of interventions to prevent perinatal transmission. Communities can then develop and implement improvements to systems of care for women with HIV infection and their infants.

The first step in implementing this methodology in a community is **gathering necessary partners**, which should include healthcare providers, agencies, public health officers, as well as community organizations and advocates from both the MCH field as well as the HIV/AIDS field. Throughout the pilot, HIV/AIDS clinical care providers and case management agencies tended to be instrumental in case identification and the MCH professionals' previous experience with the FIMR process ensured fidelity to the methodology. The collaboration between disciplines helped with data collection by increasing the potential sources of data, and expanded the types of recommendations beyond what would have resulted from a less diverse team of professionals.

The table below summarizes the key components of carrying out this methodology, once the necessary partners have been engaged.[4] The lead agencies/individuals will need to determine a process of **identifying cases**, designate who will do **data abstraction from medical records**, and who will conduct the **maternal interviews**. All of the information gathered on each case is reviewed by the **Case Review Team (CRT)**, which makes recommendations for the **Community Action Team (CAT)** to implement.

[3] Funding agreements #65/CCU323377-03/04 and # 5U65PS000813-01 from the Centers for Disease Control and Prevention, and cooperative agreement TS-1352 with the Association for Prevention Teaching and Research.
[4] For more a more thorough description of the five project pillars, please refer to the attached FIMR/HIV Prevention Methodology protocol document (see Appendix A).

Some communities may already have a functioning group that includes a broad membership of local MCH and HIV leadership that can assume the role of CRT, CAT, or both. Still, findings from an evaluation of the national FIMR program indicate that a two-tiered structure for FIMR, made up of separate CRT and CAT members, appears to enhance the program's effectiveness. Communities using the FIMR/HIV Prevention Methodology are strongly encouraged to implement the two-tiered system. The key is to have a CRT capable of fully analyzing information about the care and services received by a mother with HIV infection before, during and after her pregnancy and a CAT composed of individuals with enough political will, influence and expertise to implement some, if not all, of the CRT's recommendations.

DATA COLLECTION	
Case Identification & Selection	Case Definition: HIV-exposed infant/fetus ≥ 24 weeks gestation and < 24 months of age at the time of the review Cases for review are prioritized for each community, not randomly selected Cases are selected based on key indicators of missed HIV prevention or treatment opportunities, such as: • HIV-infected infant • Late maternal HIV diagnosis in the prenatal period • Lack of, or inadequate, prenatal care • Lack of maternal HIV treatment or poor viral suppression during pregnancy • Lack of antiretroviral prophylaxis during labor and delivery
Case Abstraction	All available medical, hospital, public health and case management records are reviewed Information is abstracted from the birth certificate and the following medical records: maternal HIV care, prenatal care, labor and delivery care, newborn care, post-partum/reproductive health care, and pediatric care (birth – 6 months All information is de-identified

Maternal Interview	Sites determine the appropriate person(s) to conduct maternal interviews Information gathered includes prior HIV risk, pregnancy, labor and delivery, post-partum care, etc. All information is de-identified
ORGANIZATIONAL STRUCTURE	
Case Review Team (CRT)	Role: Review all information gathered for each case; identify systems issues and make recommendations for improvement A multidisciplinary team (representing a broad range of providers, institutions, community advocates, professional organizations, and private agencies that provide services for women, infants and families) is essential Conduct regularly scheduled case reviews (e.g., monthly) During the review of cases, strengths in the care provided to the mother, opportunities for improvements to care, and general systems issues are identified Create recommendations to improve systems
Community Action Team (CAT)	Role: Initiate systems change based on CRT findings and recommendations "Champions" within the community are important Include a broad-based, multi-partner range of community leaders that represent the diverse ethnic and cultural groups in the community Should be composed of two types of members: those with the political will and fiscal resources to create large-scale systems change and those who can define community perspectives on how best to create the desired change in the community Should include representatives with influence over maternal and child health systems as well as HIV prevention and care systems

NEXT PHASE

Based upon the success of the pilot project, City**M**at**CH**, CDC and ACOG/NFIMR encourage communities interested in improving systems of care for women with HIV infection to utilize this methodology. Because of the intensive nature of this work, interested communities are required to submit an application to participate, documenting readiness to take on this work. All selected communities will receive technical assistance from CDC, City**M**at**CH** and ACOG/NFIMR, and will form a learning practice community to share ideas and problem-solve with one another. Some funds are available to support this work, and will be awarded based upon demonstrated need (described in the applicant instructions section).

PROJECT TIMELINE

Accepted communities must commit to participating in implementation activities for 12 months.

July 2009	RFA released online
August 11, 2009 (2:00-3:30pm Eastern)	Informational conference call held
August 28, 2009 (12:00 midnight Pacific)	Applications due
September 2009	Communities selected and notified
October 2009	Training calls held with core teams
October - December 2009	Complete IRB process where applicable (a non-research determination was made by CDC, therefore this work is exempt from CDC IRB review) Identify people for data abstraction/maternal interviews Assemble case review team (CRT) Training and technical assistance calls
January 2010	On-site training held
January 2010 – March 2010	Begin data abstraction and maternal interviews Conduct at least one full CRT meeting Ongoing training and technical assistance calls Select sites visited by City**M**at**CH** and ACOG/NFIMR
April 2010 - September 2010	Continue data abstraction and maternal interviews Hold regular CRT meetings Assemble the community action team (CAT) Ongoing training and technical assistance calls Select sites visited by City**M**at**CH** and ACOG/NFIMR
On-going	Continue data abstraction, maternal interviews, and case reviews Hold regular CAT meetings
October 2010 (Year 1 report)	Generate a final written report Share findings/results at selected venues

BENEFITS OF PARTICIPATION

- Improved systems of care for women with HIV infection and their children
- Prevention of future perinatal HIV cases
- Ongoing technical assistance to implement the FIMR/HIV methodology (conference calls, site visits and various opportunities for additional trainings)
- A forum to network, share ideas and problem solve with colleagues nationwide working on similar issues
- Information from leading experts in the fields of MCH and HIV/AIDS
- Access to an online resource library of materials, a data entry and report generating system, on-going guidance from national partners, etc.
- Possible funding to implement project (see "Funding and Resources" in the applicant instructions below)

EXPECTATIONS OF PARTICIPATING SITES

- Implement the FIMR/HIV process and document findings, recommendations and actions
    - Apply systems for case finding and maternal interview
    - Document in writing: number of cases reviewed, findings from each case and trends over time, recommendations and community actions
    - Survey women's health, prenatal and preconception care sites to inventory HIV resources, health education messages, screening protocols, health care services, etc.
    - Engage stakeholders in the community (previous, current and new partners)
    - Recruit active participants for the Case Review Team and the Community Action Team
    - Make plans for continued sustainability

- Participate fully in sponsored project activities including conference calls and on-site meeting
    - Share results and experiences gained with partners and other participating sites

MINIMUM ELIGIBILITY CRITERIA CHECKLIST

- ☐ Ability to identify cases of HIV-infected pregnant women and their infants, particularly HIV-infected infants
- ☐ Demonstrated capacity to collect information, interview mothers and complete 25 - 35 case reviews per year

Please note that preference will be given to communities that possess one or more of the following elements:

- ☐ Access to local existing FIMR program and expertise
- ☐ Elevated burden of HIV, particularly HIV infection among women
- ☐ Appropriate partners represented, and collaboration between MCH and HIV communities is present or possible
- ☐ Successful track record of promoting community action around HIV and/or MCH
- ☐ Commitment of existing resources (i.e. funding and staff) to implement the project

APPLICANT INSTRUCTIONS

1. **Statement of Need (2 Page Limit)**
    a. Describe the need for your community to address HIV infection and perinatal HIV exposure and transmission specifically. Explanation should include the most recent data available or an explanation for the lack of data and how the project will aid with data availability.

2. **History of FIMR (2 Page Limit)**
    a. Provide information regarding local Fetal and Infant Mortality Review (FIMR)[5] history and rationale for using FIMR to address perinatal HIV exposure in your community. If applicable, discuss how the two FIMR programs can work cooperatively, avoiding duplication of team members and staff. Include examples of community action and systems changes that have resulted from FIMR in your community.

3. **Leadership of Proposed Core Team (Complete table below)**
    a. Provide information regarding the two individuals from the MCH and HIV communities who will guide and organize efforts at the local level. Using the table below, list professional background and anticipated responsibilities. Note: It may be beneficial to your work to have co-leaders with different areas of expertise (e.g. perinatal HIV coordinator, FIMR coordinator, infectious disease epidemiologist, Ryan White Part D director, Healthy Start Director, Health Department MCH professional, etc.) as applicable to your community.

Team Leadership *Include name, agency affiliation, and area of expertise (HIV/AIDS, MCH, FIMR, etc.)*	**Responsibilities** *What will this individual contribute to the work? Include specific tasks related to the work.*
1.	
2.	

[5] For more information regarding the Fetal and Infant Mortality Review (FIMR) methodology, visit www.nfimr.org.

4. **Potential for HIV/MCH/Community Collaboration**
    a. Explain the current relationship between MCH and HIV services in the community. Describe the potential for engaging community partners, and strengthening the relationship between MCH and HIV services. **(1 Page Limit)**

    b. In the table, list possible organizations and/or individuals who will be involved on the case review team (CRT), the community action team (CAT) or any other aspect of this work. **(Complete table below)**

Partners *Name of agency and/or specific individuals who will be involved with this work.*	**Anticipated Role** *What will this agency or individual contribute to the work? In what aspects of the work (overall, CRT, CAT)?*	**Current Relationship & Commitment to this Work** *Describe current working relationship and collaborative work. If none, to what extent have they expressed interested and/or commitment to carrying out this work?*
1.		
2.		
3.		
4.		
5.		

5. **Letter of Commitment (no limit; Please attach)**
    a. Provide a letter from the leadership team (complete with signatures) indicating commitment to implement the FIMR/HIV methodology within the local community. Additional letters of support from the MCH and HIV provider communities and other local organizations and advocates are strongly encouraged.

6. **Funding & Resources**

Please indicate whether your community is applying for participation with funding or participation without funding. Select one of the options below:

☐ **Statement 1: We will be able to carry out this work with local funding and resources (non-funded site).**

Note: non-funded sites will be required to use their own funds to implement project work. These sites will also be required to have at least one team member attend the on-site training to be held in January 2010. Funding may be available to travel additional team members to on-site training.

- Please briefly describe the source(s) of funding, resources, and personnel that you will use to carry out this work.

☐ **Statement 2: We would like to be considered for funding from CityMatCH and ACOG.**

*Note: City**M**at**CH** and ACOG will provide start-up funds to selected sites to implement this methodology. Additionally, City**M**at**CH** and ACOG will support travel for some team members to attend the on-site training to be held in January 2010.*

- Please attach a program budget (see Appendix B). *Selection of funded sites will be determined based on efficient use of all program funds and resources. Funding awards will be based on documented need, with a ceiling of $30,000 and an anticipated award level of $22,500 (one-time award for 12 month project). Year two continuation funding may be available.*

- Please describe all local resources that you have to support this work (personnel, expertise, etc.). Also list any other perinatal HIV funds, such as CDC perinatal HIV prevention funds, that come into your local community.

Please submit all application materials electronically to Brenda Thompson at CityMatCH. The full application must be completed and received by Midnight (Pacific time) August 28, 2009. Additional questions and comments can be directed to Brenda Thompson at brendathompson@unmc.edu or Jennifer Martens at jlmartens@unmc.edu. You may also call the City**M**at**CH** main office (402) 561-7500.

FIMR/HIV PREVENTION METHODOLOGY

Appendix A. Project Protocol

This FIMR/HIV Prevention Methodology Protocol describes how participating sites will conduct their work based on five project pillars. Each participating community will need to determine specific details for each step of this protocol, taking into account specific community factors, organizations, and people necessary to carry out the work. The protocol will be updated as needed based upon continued evaluation of the experience in the pilot sites and the experiences of new communities implementing the methodology.

Technical assistance from City**M**at**CH**, ACOG/NFIMR and CDC in the form of teleconferences, site visits and an in-person training will be made available to sites implementing the FIMR/HIV Prevention Methodology. Additionally, sites will have access to resources on the City**M**at**CH** website.

1) Case Identification

For this methodology, a case is defined as, "HIV-exposed infant/fetus ≥ 24 weeks gestation and < 24 months of age at the time of the review"

To identify cases in accordance with the definition presented above, sites should build relationships with delivery hospitals in their communities. This will facilitate the primary case identification strategy, which requests that hospital employees contact FIMR/HIV staff when women with HIV infection present for delivery. Two supplemental case identification strategies have been developed:

- Develop relationships with HIV case managers and prenatal care providers who will contact FIMR/HIV staff when pregnant women with HIV infection are identified.
- Regular review of existing HIV and disease surveillance programs (e.g., HIV/AIDS Reporting System, Enhanced Perinatal Surveillance, etc) by FIMR/HIV staff to identify missed cases.

Sites are responsible for reviewing between 25-35 cases annually. A priority assessment developed during the pilot will assist sites in selecting cases for review that are likely to illustrate potential gaps in the prevention of perinatal HIV. Issues prioritized for assessment include identification of the infant as HIV infected, late maternal HIV diagnosis in the prenatal period, lack of or inadequate prenatal care, lack of maternal HIV treatment or poor viral suppression during pregnancy or lack of administration of antiretroviral prophylaxis during labor and delivery.

2) Data Abstraction

Sites will attempt to collect information from the birth certificate and the following medical records: Maternal HIV care, prenatal care, labor and delivery care, newborn care, post-partum/reproductive health care, and pediatric care (birth – 6 months). Data abstraction forms have been developed for each of these sources.

Results from the pilot project indicate that information obtained from the following four sources were the most essential: prenatal care records, labor and delivery records, pediatric care records, and maternal interview. Data from these sources permitted participants to compile complete case information that led to a high quality case review. Completion of these four data abstraction forms should be a priority for data abstractors.

3) Maternal Interview

Each site will make concerted efforts to interview the mother using the Maternal Interview Abstraction Form.

Signed consent from the mother should be obtained prior to interview. Site staff must pursue contact with a woman as soon as possible after a positive HIV screening test in order to solicit consent; however, FIMR/HIV staff should wait to conduct the interview until the diagnosis of HIV infection is confirmed. To increase the percentage of interviews conducted, sites must attempt to complete an initial interview as early as possible. Not all relevant information will be available from the mother at an early interview date (e.g., whether the infant received the entire 6-week antiretroviral regimen, the infant's infection status, etc.). Therefore, a follow-up interview should be attempted at a later time (e.g., after three months after delivery). The location and method of each Maternal Interview should be negotiated with the woman in order to best accommodate her needs and life situation.

4) Case Review Team (CRT)

Each site must convene a Case Review Team (CRT) that includes a broad range of professional organizations, institutions, and public and private agencies (e.g., clinical care providers, health clinics, welfare agencies, educational institutions, and advocacy groups) that provide services and resources for women, infants and families. The CRT should represent the diverse ethnic and cultural groups in the community and should include representatives with expertise in maternal and child health as well as HIV infection, care and prevention.

- **The purpose of the CRT:** Review all information gathered for each case; identify systems issues and make recommendations for improvement to the Community Action Team

In the review of cases, deliberations should be guided by the FIMR CRT Summary Questions (i.e. What economic, health service systems, community resources or personal factors helped this family? Did the family receive the services and resources that they needed? What are the local service delivery issues that the case highlights? Are there gaps in the system or community resources? Can more responsive community resources or service delivery systems be designed? What should they look like?).

The frequency of CRT meetings, along with their precise structure and processes, should be decided by each community in order to best tailor the work to the specific needs and circumstances of participants.

5) Community Action Team (CAT)

Each site must convene a Community Action Team (CAT) that is composed of two types of members: those with the political will and fiscal resources to create large-scale systems change and those who can define community perspectives on how best to create the desired change in the community. The CAT should include representatives with influence over maternal and child health systems as well as HIV prevention and care systems. In general, CRT and CAT membership will not include the same people, as too much overlap in membership could result in individuals being overburdened. However, each community can determine the composition that is most effective and relevant to their situation.

- **The purpose of the CAT:** Initiate systems change based on CRT findings and recommendations.

As with the CRTs, the frequency of CAT meetings, along with their precise structure and processes, must be decided by each community in order to best tailor the work to the specific needs and circumstances of participants.

FIMR/HIV PREVENTION METHODOLOGY

Appendix B. Budget Guidance

Example Cost Categories	Item Description
Salaries & Wages	
FIMR Coordinator	Responsible for technical assistance, data entry/analysis, and CRT staffing
Project Director	Responsible for project oversight, reports, and CAT staffing
Administrative Assistant	Responsible for coordinating mailings and meeting support
Case Abstractor	Responsible for case abstraction and data collection
Maternal Interviewer	Responsible for maternal interviews and any follow-up
Other Expenses	
Mileage Reimbursement	Local travel for maternal interviewer and other project staff
National Training	Travel for 2 project staff to attend national on-site training in January 2009 (location TBD)
Printing/Duplication	Printing/duplication costs for CRT and CAT meeting materials
FIMR/HIV Final Report	Costs to generate and print final report to distribute to local partners and stakeholders
Postage	Postage needed for CRT/CAT mailouts
Interview Incentives	Incentives for mothers completing the maternal interview
Cell Phone Reimbursement	Provided to interviewer to ensure safety during home visits

Please include a budget justification that indicates the basis for your cost estimates. Include the local resources committed as well as the funds requested for each expense.

FIMR/HIV PREVENTION METHODOLOGY

Appendix C. Application Review Criteria

Please note that preference will be given to communities that demonstrate one or more of the following elements in their application:

- Access to local existing FIMR program and expertise
- Elevated burden of HIV, particularly HIV infection among women
- Appropriate partners represented, and collaboration between MCH and HIV communities is present or possible
- Successful track record of promoting community action around HIV and/or MCH
- Commitment of existing resources (i.e. funding and staff) to implement the project

The decision to fund any community is within the discretion of the review committee and submission of an application does not guarantee approval of funds. All complete applications will be reviewed and scored based on the following elements:

1. **Statement of Need (15%):** *The extent to which the application describes the need to address perinatal HIV in the community.*

2. **FIMR Capacity (10%):** *The extent to which the application provides information regarding local Fetal and Infant Mortality Review (FIMR) capacity, resulting in community action or systems changes.*

3. **Leadership of Proposed Core Team (20%):** *The extent to which the application elaborates on the proposed core team members' ability to guide and organize efforts.*

4. **Potential for HIV/MCH/Community Collaboration (30%):** *The extent to which the applicant explains the potential for strengthening the relationship between MCH and HIV services through local perinatal HIV case identification, case review and community action...*

5. **Letter(s) of Commitment & Support (10%):** *The extent to which the letter(s) describe(s) organizational commitment by a diverse group of interested partners to implement the FIMR/HIV Prevention Methodology.*

6. **Justification of Budget (15%):** *The extent to which the program budget narrative documents efficient use of funds and resources.*