ELIMINATING MOTHER-TO-CHILD HIV TRANSMISSION: IT’S WITHIN OUR REACH
Welcome to this special edition of CityLights, exploring the issue of preventing mother-to-child transmission of HIV (PMTCT). PMTCT is unique in that it requires collaboration between HIV and MCH experts. The articles that follow are a collective call to action on this issue, which has been identified as a winnable battle by the Centers for Disease Control and Prevention (CDC).

The CDC has developed a national goal of eliminating mother-to-child HIV transmission, and we are inching ever closer. Although great strides have been made in preventing new HIV infections in infants, local and state health departments still have much work ahead of them. Data show that mothers of infected babies experience at least one missed opportunity for perinatal HIV prevention, including no or inadequate prenatal care; a late diagnosis of HIV infection; and a lack of appropriate antiretroviral medication. We must ensure that women of childbearing age who are living with HIV have access to family planning and preconception care services, a key component in the elimination framework. With appropriate interventions and successful collaboration, the risk of mother-to-child transmission of HIV can be reduced to less than 1%.

However, the CDC reports that between 120,000 and 160,000 women of childbearing age in the United States are infected with HIV, and 15 percent of these women do not know their HIV status. This of course puts them at a higher risk of transmitting the virus to their babies. In addition, HIV testing of pregnant women remains inadequate. When women do test positive and are engaged in care, that care rarely includes reproductive health care and family planning services. All these data indicate more work needs to be done if we are to seize the opportunity in this winnable battle. The work of health departments to sustain this important perinatal HIV prevention work becomes increasingly vital. With your help, we can achieve our goal of elimination.

The Centers for Disease Control and Prevention and a diverse group of key stakeholders have developed a framework to eliminate mother-to-child HIV transmission (EMCT) in the United States. Successful implementation of the framework requires strong collaboration among governmental and non-governmental stakeholders, particularly those in the maternal and child health (MCH) community. The EMCT plan incorporates the three primary goals of the National HIV/AIDS Strategy (NHAS) to reduce new HIV infections: increase access to care, improve health outcomes for people living with HIV, and reduce HIV-related disparities.

Fifty experts from federal agencies, state and local health departments, clinical care settings and national professional organizations are working in six complementary workgroups to implement the framework. Each workgroup represents an essential functional aspect of the EMCT plan (See Figure 1). The workgroups’ activities involve a variety of initiatives, almost all of which either include or benefit MCH services at the local level (See Figure 2, pg 4).

While the work of the stakeholders’ group is national in scale, it is critical to get local involvement in a number of the current initiatives. One specific way local MCH can get involved is through the FIMR/HIV Prevention Methodology. The FIMR/HIV Prevention Methodology (FHPM) is based...
upon the Fetal & Infant Mortality Review (FIMR). FIMR is an action-oriented community process that continually assesses, monitors, and works to improve service systems and community resources for women, infants, and families (See Figure 3).

By collecting comprehensive quantitative and qualitative data about the pregnancy experiences of women with HIV infection, the FHPM provides an in-depth look at the systems that result in a perinatal HIV exposure or transmission. This 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.

There are currently six sites implementing FHPM with a new cohort of sites starting a FHPM project. While the FHPM sites all implement the methodology differently, one thing is consistent: the presence and critical importance of local MCH on every FHPM team. FHPM specifically looks at gaps in services for pregnant women living with HIV, and the MCH presence on FHPM teams can help address these gaps. Furthermore, it has been discovered that FHPM can help shed light on perinatal systems gaps all women encounter, so the MCH presence on FHPM teams can help to improve perinatal health systems for ALL families, not just for women living with HIV.

The FHPM provides a concrete way for local MCH to get directly involved in perinatal HIV efforts, but there are a variety of other ways that MCH leaders can be involved in perinatal HIV elimination strategies (See Figure 4).

Integrating the EMCT framework into MCH services provides MCH with both the opportunity to mainstream HIV services for pregnant women and children, and to apply the lessons learned to other MCH programs and vulnerable populations. The work of the EMCT Stakeholder group has resulted in improvements in care for ALL women, as demonstrated by the FHPM, but the only way to continue these improvements is to expand the support and involvement of MCH leaders. With the help of MCH, the stakeholders group can achieve its goal of eliminating mother-to-child transmission in the United States.

To learn more about the elimination of mother-to-child HIV transmission in the United States, please visit www.cdc.gov/hiv/risk/gender/pregnantwomen.

---

**FIGURE 2. Current Activities of the EMCT Stakeholders Group**

- Defining outcome and performance measures for delivery of reproductive care for HIV-infected persons and for use within Ryan White* and Title X programs;
- Implementing quality measures for HIV testing of pregnant women in labor and delivery;
- Developing and disseminating clinical and psychosocial standards for EMCT comprehensive care and case management;
- Implementing a modified FIMR-HIV methodology for case review and community action for HIV exposure (and other perinatal infections in lower HIV-incidence areas);
- Doing a qualitative study of breastfeeding and retention in postpartum HIV care in HIV-positive women;
- Working with Healthy Start sites to develop educational material on breastfeeding messages for HIV-infected women

*The federal Ryan White CARE Act improves the quality and availability of care for individuals and families affected by HIV disease.

---

**FIGURE 3. The FIMR/HIV Prevention Methodology**
To learn more about the elimination of mother-to-child HIV transmission in the United States, The FHPM provides a concrete way for local MCH to get directly involved in perinatal HIV efforts, but there are a variety of other ways that MCH leaders can be involved in perinatal HIV systems gaps and support the integration and coordination of services for women and children with HIV infection and children and families with special health care needs.

- Comprehensive Clinical Care: MCH can identify areas where MCH and HIV programs serve overlapping vulnerable populations and support the integration and coordination of services for women and children with HIV infection and children and families with special health care needs.

- Reproductive Health, Family Planning Services and Preconception Care: MCH can identify best practices and successful protocols for the integration of preconception counseling and care with primary care and chronic disease.

- Case Review and Community Action (FIMR/HIV Prevention Methodology): MCH can partner with FIMR programs and FHPM programs to share expertise and resources.

- Research and Long-term Follow-up: MCH can identify and share EMCT research questions and data needs and facilitate collaborations among researchers and clinicians.

- Data and Surveillance: MCH can provide educational and technical assistance, and disseminate data to healthcare providers through reports, presentations, and publications.

The FIMR/HIV Prevention Methodology is a community-based, case review approach to identify and address systems issues contributing to mother-to-child HIV transmission. The goal of the FIMR/HIV Prevention Methodology (FHPM) is to improve perinatal HIV prevention systems by using the Fetal & Infant Mortality Review (FIMR) case review and community action process.

The FHPM is a five-step process:

- Case Identification: Cases are prioritized which illustrate potential gaps in prevention of mother-to-child transmission and indicate a missed opportunity for perinatal HIV prevention.

- Medical Record Abstraction: Medical record abstraction forms are developed to provide an in-depth look at the care a woman received, and data is collected from maternal and infant medical records on maternal HIV care, prenatal care, labor and delivery care, newborn care, postpartum care, and pediatric care.

- Maternal Interview: A maternal interview is completed to allow the mother to provide her story about her pregnancy as well as her prenatal and HIV-related care, exposing potential systems gaps.

- Case Review Team: Selected de-identified cases are reviewed with a multi-disciplinary team (the Case Review Team, or CRT) and recommendations are developed to address system issues.

- Community Action Team: The Community Action Team, a group of clinicians and community leaders, is convened to review the CRT’s findings, develop a plan for community action based on the CRT’s recommendations, and mobilize the community to ensure implementation.

For more information, contact Erin Schneider at e.schneider@unmc.edu or 402-552-9583. To learn more about Perinatal HIV or the FIMR/HIV Prevention Methodology, visit the FIMR/HIV Prevention Methodology National Resource Center online at http://www.fimrhiv.org.
### Sample of MCH-Related Findings and Recommendations from the FIMR/HIV Sites

Below are some of the findings, or systemic gaps, and recommendations for change from FIMR/HIV sites between 2009-2012

<table>
<thead>
<tr>
<th>FInding</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prenatal care is limited to Emergency Department visits</td>
<td>Assist EDs with linking pregnant women to ongoing HIV care; Provide community education on the importance of prenatal care</td>
</tr>
<tr>
<td>Lack of transportation is a barrier to prenatal visits</td>
<td>Create a one-stop center for women with HIV; Conduct cross-training for physicians offering OB and HIV services</td>
</tr>
<tr>
<td>Non-English speaking women are unable to understand their providers’ information.</td>
<td>Create culturally competent educational resources; Ensure that a mechanism to access non-relative translators is in place in hospitals</td>
</tr>
<tr>
<td>Mothers are not offered contraception education and prescriptions in hospitals</td>
<td>Offer contraception forms after deliveries and provide education; Primary Care physicians should incorporate Family Planning counseling into all visits</td>
</tr>
<tr>
<td>HIV positive patients are not receiving Family Planning counseling</td>
<td>Offer reproductive health counseling during all HIV care</td>
</tr>
<tr>
<td>Routine newborn care education is not offered during hospital discharge teaching</td>
<td>Teach newborn care along with information around infectious diseases and medication administration</td>
</tr>
<tr>
<td>A large delay in HIV care exists for mothers after delivery</td>
<td>Conduct an analysis using HIV surveillance data to track Maternal HIV care after pregnancy</td>
</tr>
<tr>
<td>Mothers are lost to follow-up when their child is placed in foster care</td>
<td>Use existing resources in the family center care programs to conduct outreach to mothers</td>
</tr>
<tr>
<td>A need exists for mental health assessment and linkage to care</td>
<td>Provide counseling and education about mental illness when there is a family history; providers should increase knowledge about available options and referrals for identified depression</td>
</tr>
</tbody>
</table>
For over four years, nine urban areas from across the United States have participated in the FIMR/HIV Prevention Methodology (FHPM) to better understand the systems-level factors and complex life circumstances contributing to mother-to-child HIV transmission (MCT). Data is available from seven of the nine participating sites. These data summarize the case reviews, demographic characteristics, and key findings of seven of the nine urban areas from their 2009-2012 project period.

Many women who live with HIV have complex health care needs and may also have complex life circumstances. When project teams identify a case for review (see Table 1), they abstract information from the woman’s health care records using a number of different data sources. These data sources, however, often give an incomplete picture of the woman’s day-to-day life. Project teams supplement their knowledge about the woman and her life circumstances by conducting a maternal interview. Through interviews, the woman provides a more complete picture of her life before, during, and after her pregnancy to help the FIMR/HIV teams better understand her prenatal care, HIV care, labor and delivery, and the pediatric care of her baby. During the project period, in the seven communities where the data was available, the FIMR/HIV prevention projects reviewed 181 cases and conducted interviews with 49% of the women.

While every mother-to-child HIV exposure and transmission can provide insight into service systems, project teams often need to prioritize the cases they review. In order to do this, teams use a priority assessment to determine which cases are selected to review. The priority assessment helps sites to pick cases that fully capture systemic gaps and can help shape recommendations for improvement. In addition to the priority assessment, sites also have used the following considerations to prioritize their case review:

- Pregnancy intendedness at time of conception;
- HIV status of the infant;
- Maternal co-infections (for example, syphilis, gonorrhea, hepatitis B and hepatitis C); and
- Missed opportunities for intervention (for example, maternal substance use, mental illness, homelessness, mother lost to care following delivery, lack of referrals for post-partum or pediatric care).

Of the 181 infants born to the women in the project, 13% tested positive for HIV, 78% tested negative for HIV, and 9% had an indeterminant HIV status (see Table 2).
Characteristics of the Women

Women in the project ranged in age from 15 years to over 40 years (see Figure 1). Over 75% of the women were between the ages of 20 and 34 years. Of the women who participated in the project, a disproportionate number were African American women. Over 76% were African American/Black, 11% were White, and 8% were born outside of the United States (see Figure 2). None of the women were Hawaiian/Pacific Islander or Native American/Alaska Natives. This mirrors the epidemic nationally where the number of new HIV infections in women is highest in the African American community. It is estimated that 1 in 32 African American women will be diagnosed sometime in their lifetime with HIV.1

Project teams reported that the ethnic composition of the women was:
- 5.5% Hispanic/Latino;
- 81.2% Non-Hispanic/Latino; and
- 13.3% unknown.

A common finding among the sites was a need for increased access to contraception and family planning education. Many sites reported that the pregnancies were unintended. The data found during the case reviews supports these findings. Women reported the total number of times that they had delivered a live born infant:
- 24.9% had one live birth;
- 23.2% had two live births;
- 18.6% had three live births; and
- 33.3% have four or more live births.

As the largest percentage of women had given birth four or more times, there may be a need for information on family planning (both postpartum and during HIV care) and a need for increased contraception access among women living with HIV.

Nationally, the HIV prevalence rate of HIV positive people is high among urban areas with high levels of poverty.2 The FIMR/HIV projects had similar findings, with the highest percentage of women participating in FIMR/HIV living in extreme poverty (see Figure 3):
- 32% earned less than $8,000 per year;
- 10% earned between $8,000 and $19,999 per year;
- About 4% earned $20,000 or more; and
- About 46% had unknown income earnings.

Employment data was known for only 69 of the 181 women. Reflective of the overall income of many of the women in the project, only 14% of women were employed at any time during pregnancy. Twenty-four percent (24%) were not employed during pregnancy.

Key Findings from the FIMR/HIV Process

Project teams identified a number of issues that need to be addressed from a systems perspective to improve maternal care and prevent MCT (see Table 3). The sites also made a number of recommendations to address these identified issues. Some of the recommendations require only a slight
change in practice, documentation or protocol. For example,

- Improving provider documentation regarding HIV testing and status;
- Providing education on the importance of prenatal care, available services, current recommendations, and prevention of mother-to-child HIV transmission; and
- Developing protocols for referrals.

Other recommendations, however, require broader policy change and addressing social determinants of health. For example,

- Increasing awareness, training, and conducting screening, brief intervention, and referrals for intimate partner violence, mental health / depression, and substance abuse;
- Increasing access to family planning; and
- Addressing housing issues for HIV positive women and HIV positive pregnant women.

**Lessons Learned in Preventing Mother-to-Child Transmission**

Through the FHPM, we have been given a snapshot of the complex and challenging world of some women who are pregnant and HIV infected. Often these women live in complicated and stressful life situations while navigating a life-long, chronic illness. Many of these women are experiencing unstable housing situations, interpersonal violence, and/or mental health and substance abuse issues. They are living well below the poverty line and do not have consistent medical care, let alone HIV care. Because of these life circumstances they often lose custody of their children and quietly fall through the cracks of the system.

The cases reviewed for FHPM can appear bleak and hopeless. These cases, however, shed light on the lives of some of the most vulnerable and underserved members of our society. Most importantly, the issues being found through FHPM are not new or unique to women living with HIV.

The FHPM provides a forum for community leaders, from HIV, MCH, and a variety of other sectors, to come together to address these large systemic issues that no one entity can tackle alone. The FHPM brings together unlikely partners to create unique solutions that can make true change happen in communities. As evidenced by the key findings above, the systemic change occurring in these communities is having an impact on a variety of HIV and MCH services.

This work is not only important in the fight to eliminate mother-to-child transmission, but it is also improving care for ALL women and children.

For more information on any of the above, please contact Erin at e.schneider@unmc.edu.

**Acknowledgement**

A special thank you to Laurin Kasehagen for all her help with the data analysis in this article.

**Table 3. Issues that Need to Be Addressed from a Systems Perspective**

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Testing &amp; Notification</td>
<td>Education from providers and patients (prenatal care, HIV care and treatment)</td>
</tr>
<tr>
<td>Primary Care</td>
<td>(maternal HIV, infant HIV, mental health, substance abuse)</td>
</tr>
<tr>
<td>Preventive Care</td>
<td>(mental health, family planning, preconception health, maternal post-partum care, intimate partner violence, infant care, breastfeeding)</td>
</tr>
<tr>
<td>Policies, Procedures &amp; Documentation (HIV testing, HIV referral and follow-up, HIV care)</td>
<td>Systems Infrastructure (access to care, patient assistance, translation, case management services)</td>
</tr>
<tr>
<td>Social Determinants of Health</td>
<td>(housing, access, transportation)</td>
</tr>
</tbody>
</table>

In the spring of 2010, the Illinois Department of Public Health and its team of community partners began working on the FIMR-HIV project. This marked the beginning of a transformational process toward improved healthcare for HIV-positive mothers in Illinois. The project team consisted of twenty-nine members recommended by representatives from the Pediatric AIDS Chicago Prevention Initiative and the Perinatal Rapid Testing Implementation Initiative in Illinois, as well as Dr. Mildred Williamson from the Illinois Department of Public Health. Team members represented thirteen public and private organizations, bringing their unique expertise and perspective to the FIMR-HIV process.

Over three months, the project team strategically reviewed fifteen cases that met one or more of the following criteria:

- An infant with a confirmed HIV positive diagnosis;
- The death of a pregnant mother who was HIV positive;
- Death of an infant born to an HIV positive mother;
- Or a known missed opportunity in an otherwise successful birth to an HIV positive mother.

Eight of the fifteen cases included a maternal interview. These confidential interviews gave the mothers a voice in the FIMR-HIV process and helped the team consider systems of care from the deeply valuable perspective of the mother herself. After reviewing these cases, the team generated a list of major findings (See Figure 1).

Based on the findings, the Case Review Team (CRT) recommended the following five interventions for state-level mother-to-child HIV transmission prevention in Illinois: Testing, Screening, Training and Education; Quality Assurance and Medical Records; Specialized Resources and Outreach; Case Management; and Legal Mandates. The following are some of team’s key recommendations for each intervention category:

### Testing, Screening, Training and Education

The CRT suggested updating rapid HIV testing protocols for pregnant women at all birthing and non-birthing hospitals in Illinois, building upon the original Perinatal Rapid Testing Implementation Initiative (PRTII) rapid testing resource binder. Other recommendations included:

- Utilizing PRTII staff to offer technical assistance, and disseminating the rapid HIV testing protocols through the perinatal network
- Making rapid testing the standard of care when a pregnant patient presents at an Illinois hospital with an unknown HIV status, and to note and immediately flag a patient for rapid testing when they present to an Illinois hospital without a record of prenatal care
- Developing a standard protocol for the labor and delivery care of HIV positive pregnant women (for both known positives and rapidly diagnosed women) at all Illinois hospitals

### Quality Assurance and Medical Records

The team recommended linking the FIMR-HIV case review process to Risk Management or Quality Assurance departments.
at all hospitals. Further, the team recommended:
• Developing a follow-up protocol when a hospital needs to implement corrective action plans in response to an issue onsite, to ensure that such actions are appropriately implemented and reviewed
• Starting the antiretroviral drug Zidovudine (ZDV or AZT) at the initial hospital and following-up in the receiving hospital, whenever an HIV positive woman is transferred from one hospital to another during delivery
• Incorporating HIV status/HIV test pending into the hospital/ambulance transport log, if the patient has been tested, to prepare the receiving hospital to act if necessary
• Ensuring that the medical records and charts reflect the reasons why an infant is not discharged with a parent after delivery

Specialized Resources and Outreach

Education and outreach should be culturally competent and tailored to reach adolescents, immigrants, refugees and non-English speaking women. The team also suggested:
• Developing peer education programs and support groups across the state
• Making reproductive health counseling available to both HIV positive pregnant women and their partners
• Providing educational resources for couples where one partner is HIV positive and the other is HIV negative
• Developing promotional and educational materials across different media formats, ranging from brochures distributed in WIC offices to websites that implement text messaging platforms

Case Management

Intensive case management should include a standardized care plan with an evaluation of key areas of urgent client needs. These areas include, but are not limited to, mental health, substance abuse, housing, corrections, and child welfare. Additionally, the team suggested:
• Requiring that intensive case management should be multiagency and include monthly staff meetings with other agencies that serve a client
• Ensuring that benchmarks are in place for entry and exit into intensive case management programs
• Training Ryan White case managers (federally funded case managers who work with persons living with HIV) throughout the state in basic perinatal case management, specifically on how to effectively link a pregnant woman living with HIV to care
• Mandating annual training updates for all case managers statewide
• Developing programs that allow step-down case management for clients who are at-risk of repeat pregnancy within one year, and those who remain vulnerable and/or are at high risk of infecting both their partner(s) and newborn

Legal Mandates

Finally, the team suggested utilizing the Illinois Perinatal HIV Prevention Act to successfully engage Emergency Departments in rapid testing. The team also proposed amending the Illinois Perinatal HIV Prevention Act (See Figure 2) with the following:
• Requiring sites to call the 24/7 Hotline when all HIV positive, pregnant women, including those with a known HIV positive status, present for delivery
• Stipulating that a minimum two-week supply of AZT syrup be made available for all mothers whose HIV-exposed babies are discharged on AZT

These are just a few of the recommended interventions from the full report which includes fifty recommendations based on the Illinois CRT’s major findings.

The Illinois FIMR-HIV experience tells a compelling story of how local jurisdictions can use the CRT process and findings to build bridges between large systems of care that often operate alongside one another without collaboration – such as MCH and HIV services. In Illinois, recommendations from the case review process are shared through the Illinois decentralized perinatal network system, so that every hospital in the state now has access to them. The synergy and collaboration created through this multi-agency process helped create many changes for the benefit of pregnant women and their children, regardless of their HIV status.

For more information on any of the above and a complete list of recommendations, please contact Anne at anne@pacpi.org or visit www.pregnantandpositive.org.

FIGURE 2. Illinois Perinatal HIV Prevention Act Highlights

• All pregnant women in Illinois presenting at a health care facility will be counseled and offered an HIV test.
• HIV test results will be documented in prenatal, labor and delivery, and newborn pediatric charts.
• If there is no documented maternal HIV status on arrival to labor and delivery, the patient will be offered a Rapid HIV test (pregnant women have the right to decline the test).
• If maternal HIV status is not known at delivery, the newborn will be given a Rapid HIV test.
• The Illinois Department of Public Health must maintain a 24 hour Perinatal HIV Hotline.
• Rapid preliminary positives from labor and delivery and triage must be reported to the Perinatal HIV Hotline and through a report form that must be completed in 24 hours.
• Hospitals must submit monthly statistics on deliveries and rapid tests to the Illinois Department of Public Health.
CityMatCH
University of Nebraska Medical Center
Department of Pediatrics
982170 Nebraska Medical Center
Omaha, NE 68198-2170
402-552-9500 • citymch@unmc.edu
http://www.citymatch.org

For questions about CityMatCH’s project and programs, contact
Denise at denise.pecha@unmc.edu or  402-552-9500

CityMatCH Staff
Chad Abresch, MEd
Executive Director
Mark Law, MS, PhD
Director of Operations
Denise Pecha, LCSW
Director of Programs

Monica Beltran, MPH PH Project Coordinator
Maureen Fitzgerald, MPA Project Coordinator
Maureen Gatere, MPH PH Project Coordinator
Carol Gilbert, MS Health Data Analyst
Laurin Kasehagen Robinson, MA, PhD Senior CDC-Assigned MCH Epidemiologist
Allison Miles, MPH Health Data Analyst
Qinge Ouyang, MS Web Designer
Rebecca Ramsey, MPH PH Project Coordinator
Janet Rogers Office Manager
Erin O. Schneider, MSW PH Project Coordinator
Jessica F. Thompson, MPH (c) PH Project Coordinator

CityLights Editors:
Anna Grignon, MA, MES
Erin Schneider, MSW
Jessica Thompson, MPH (c)

CityLights is supported in part by Grant #G97MC04442-04-00 from the Maternal
and Child Health Bureau (Title V, Social Security Act), Health Resources and
Services Administration, Department of Health and Human Services