

Perinatal HIV Transmission: Adapting the FIMR Process to Identify Opportunities for Action

Prevention of mother-child transmission of HIV has been one of the major public health successes of the AIDS epidemic. Without intervention, 20-30% of HIV-infected pregnant women transmit the virus to their infants during pregnancy or delivery. With appropriate use of antiretroviral medications and cesarean section, the rate of transmission can be reduced to 1-2%. The timely initiation of such interventions depends upon a cascade of events beginning with the woman's preconception care and identification of her HIV infection status.

In 2005, the U.S. Centers for Disease Control and Prevention (CDC) joined with CityMatCH and the National Fetal and Infant Mortality Review Program (NFIMR) to work with Jacksonville, Florida and two other cities on piloting an adaptation of a community case review process to examine the experiences of HIV+ women and their families in and around pregnancy.

The aim of the pilot project was to review, identify, address and reduce missed opportunities for providing optimum care to HIV+ pregnant women and preventing mother-to-child HIV transmission. Project partners include the Northeast Florida Healthy Start Coalition, the Duval County Health Department, the University of Florida Rainbow Center, and other community organizations working to address HIV/AIDS.

The FIMR/HIV Pilot Project is based on the Fetal and Infant Mortality Review (FIMR) methodology, which communities use to review sentinel event cases – fetal or infant deaths. FIMR has been used successfully by over 200 communities in 40 states, and has also been adapted to examine other maternal and child morbidity and mortality events. The Northeast Florida Healthy Start Coalition has implemented a FIMR Project in the Jacksonville region since 1995.

The Jacksonville FIMR/HIV Pilot Project was implemented using specific project protocols. Cases were selected for review based on the timing of the woman's diagnosis, pregnancy

Women, Infants and HIV/AIDS

Jacksonville-Duval County ranks sixth statewide in reported HIV/AIDS cases. There were 271 AIDS cases (31.7 per 100,000 residents) and 290 HIV cases reported in the county in 2005. Of the total reported HIV cases since 1997, 41% were women. African American women accounted for 33% of all reported HIV cases and an alarming 80% of HIV cases reported in women. Black women made up 78% of the female AIDS cases during this period.

For women in Jacksonville who tested positive for HIV during this period, the leading mode of transmission was heterosexual contact (75%). Nearly 80 HIV+ women become pregnant in Jacksonville annually.

Perinatal HIV Infected Babies 2004-2006.

County	Total Births	HIV Infected Births	Rate/100,000 Births
DUVAL	38,097	4	10.50
Statewide	656,507	36	5.48

Source: Florida Department of Health, 2007.

outcome, entry into prenatal care, the mother's HIV treatment status and viral load, and whether she received antiretroviral prophylaxis during labor and delivery. A total of 27 cases were selected for detailed examination in the first phase of the pilot.

Comprehensive case abstraction forms were completed on each case by contracted staff at the UF Rainbow Center. Data were abstracted from all available clinic, hospital, case management, vital statistics and related records. Data were also collected from the birth certificate. Information addressed the following areas: prenatal care, labor and delivery care, post-partum/reproductive health care, maternal HIV care, newborn care, and pediatric care. All information was de-identified and summarized by the abstractor in a case summary.

In addition to information collected from medical records, attempts were made to interview the HIV+ woman to learn first hand

about her perception of services received and any barriers to obtaining care. The interviews were conducted using a standard project questionnaire by a social worker at the Rainbow Center on about a third of the cases reviewed.

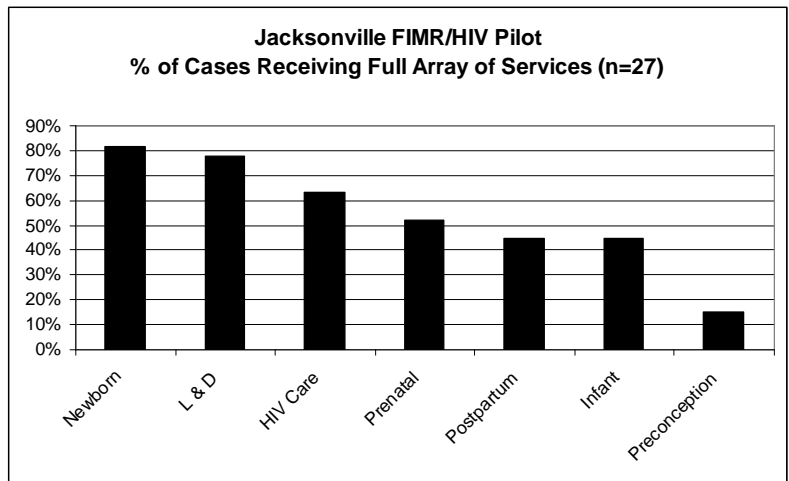
Detailed case studies were presented to a multidisciplinary case review team established for the pilot project. The team met monthly beginning in February, 2007 and reviewed 4-5 cases at each meeting. The team included prenatal and pediatric care providers, HIV/AIDS program staff, social workers and case managers, community advocates, consumers, representatives from Ryan White Part A and the First Coast AIDS Prevention Partnership, maternal and child health experts, WIC and other MCH support programs. The team completed a project form on each case summarizing strengths and weaknesses in the care provided, as well as recommendations for improving service delivery. At the end of the review cycle, the team reviewed aggregate findings on the 27 cases and developed preliminary recommendations for community action.

The next phase of the pilot is the presentation of preliminary findings and recommendations to a Community Action Team. The Ryan White Part A Planning Council and the First Coast AIDS Prevention Partnership will serve as this team, developing implementation strategies to address gaps in services and needed system improvements.

Birth Outcomes, Strengths & Contributing Factors

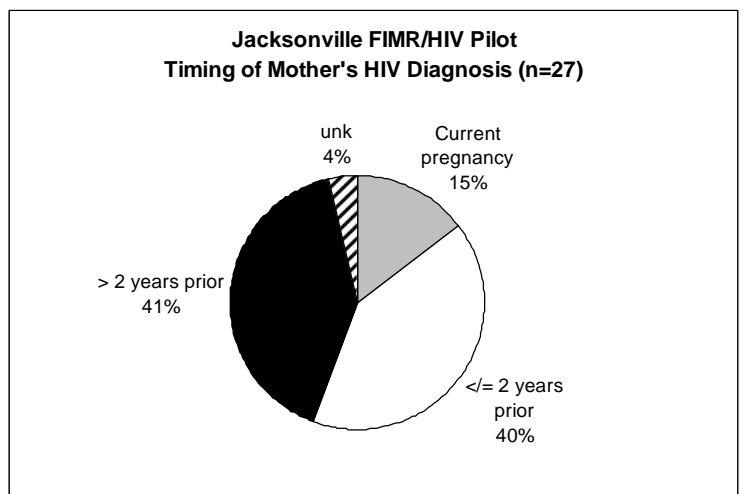
None of the reviewed cases resulted in the birth of an infected infant. One of the 27 cases resulted in a fetal loss and the death of the mother from AIDS at delivery. The 26 remaining cases resulted in live born infants.

Despite the fact that cases were selected based on criteria indicating some lapse in the receipt of care, more than 80 percent of the cases reviewed received the full array of newborn services. A majority of cases received comprehensive labor and delivery, HIV care and prenatal services.

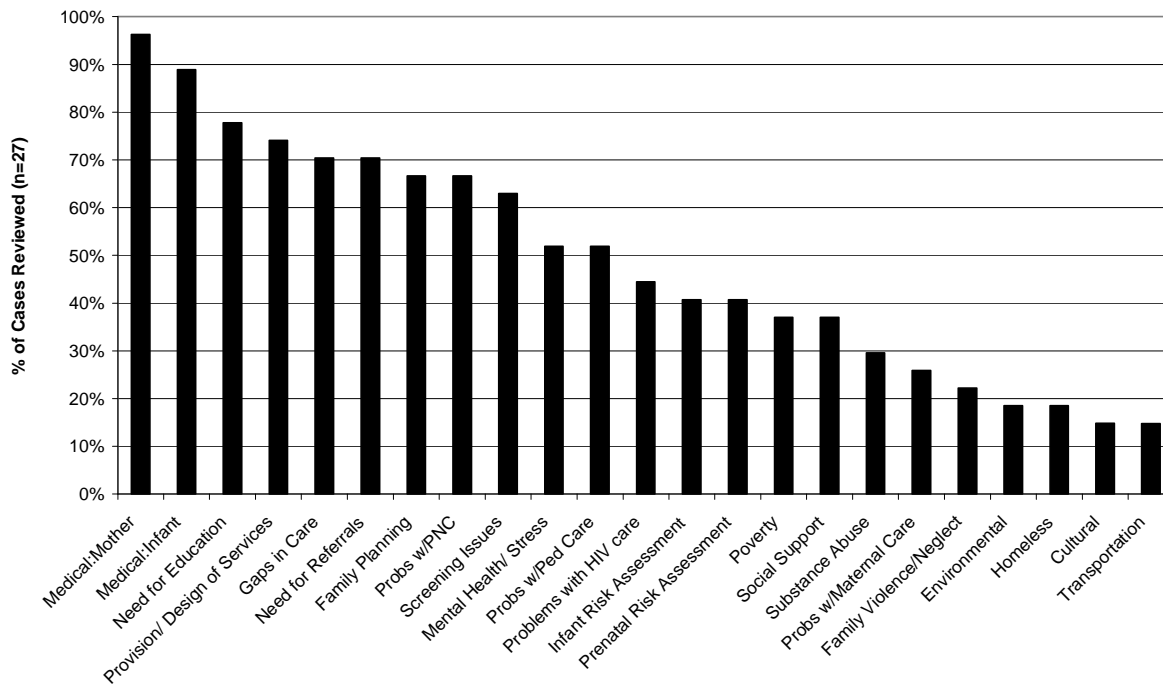


The majority of cases reviewed for the pilot project involved HIV+ mothers who were Black, age 20-25 years old, and single. Nearly 30 percent of the women received late or no prenatal care. Most of their care was paid for by Medicaid.

In about 15 percent of the cases reviewed, this was the woman's first pregnancy; in more than half of the cases the woman had 2-3 previous pregnancies. Most of the women knew their HIV status prior to the pregnancy reviewed; more than 40 percent had been diagnosed more than two years prior to this pregnancy.



**Jacksonville FIMR/HIV Pilot
Frequency of Issues Identified**



The most frequent issues identified in the preliminary case reviews are summarized in the above chart. Ninety-six percent of the cases involved some maternal medical problem, such as infection, obesity or poor nutrition. In nearly 90 percent of the cases, the infant also experienced a medical problem, including infections and pre-term delivery. The need for improved patient education, particularly addressing safe sex, family planning and birth spacing, and medication compliance was identified as an issue in nearly 80 percent of the cases reviewed.

Issues were identified with the design and delivery of services in about 74 percent of the cases reviewed. Included in this category were patient dissatisfaction with services and communication problems between providers and between patients and providers.

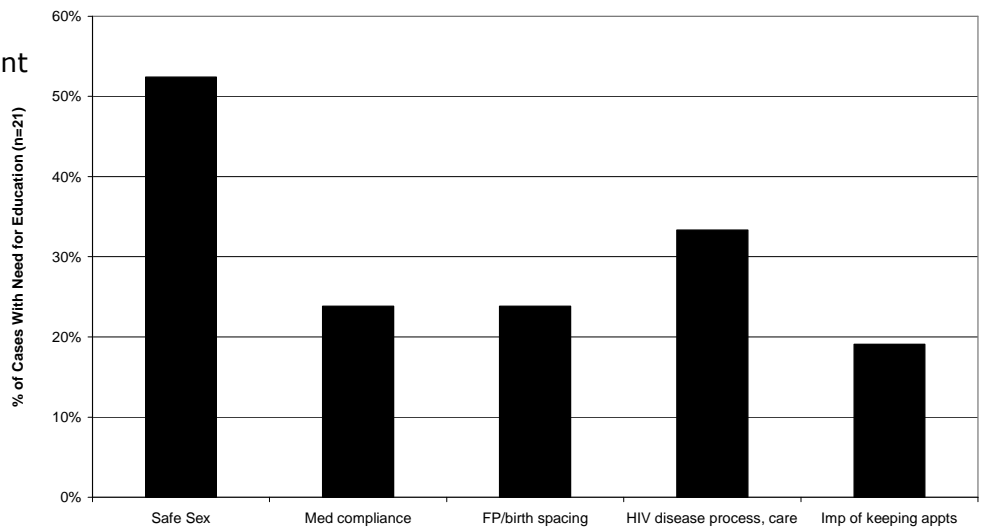
In more than 70 percent of the cases reviewed, the case review team identified gaps in services, particularly involving missed prenatal care appointments. Lack of integration between family planning, HIV and GYN care was identified as an issue in over one-fourth of the cases.

The need for referrals to mental health services, Healthy Start and/or WIC was

identified in 19 of the 27 cases reviewed.

Late entry and missed appointments were the most frequent issues identified with prenatal care in the cases reviewed for the FIMR/HIV pilot. Major issues were identified related to family planning in the cases reviewed. Half of the cases involved unintended or unplanned pregnancies. No contraceptive method was being used in more than one-third of the cases examined.

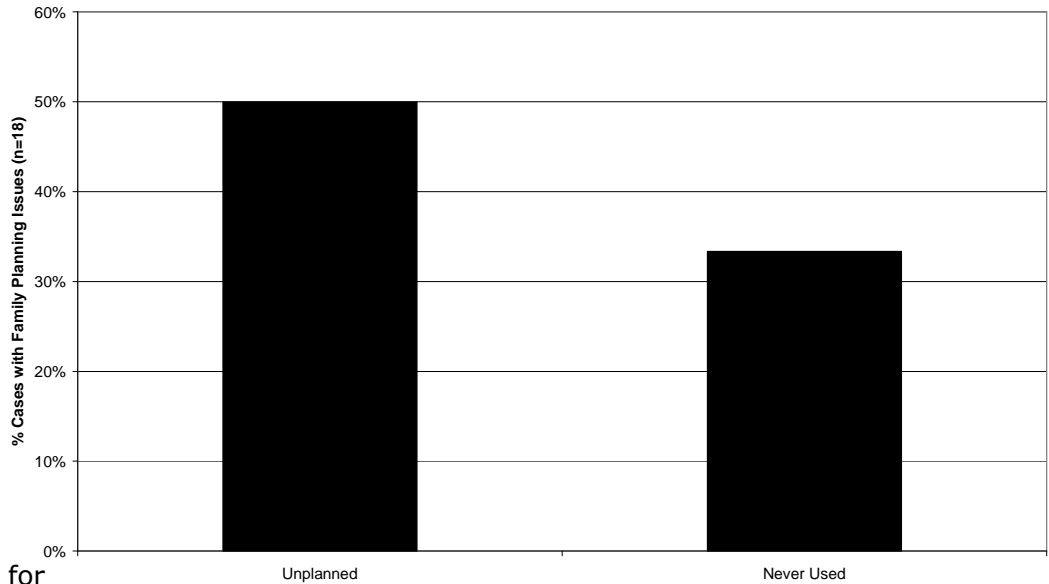
**Jacksonville FIMR/HIV Pilot Project
Need for Education
Most Frequent Problems Identified**



Preliminary Draft Recommendations

Based on its initial review of 27 cases, the FIMR/HIV Case Review team drafted the following preliminary recommendations for community action:

1. **Expand the scope of HIV care** management services to include gynecological, preconceptional and interconceptional care.
2. **Improve family planning services, safe sex education and partner referrals** for HIV+ women of childbearing age.
3. **Promote sharing** of case management information and plans across providers.
4. **Ensure the timely transfer** of records between providers.
5. **Improve follow-up** for HIV+ pregnant women who initially decline screening or services.
6. **Enhance mental health services** for HIV+ pregnant women.
7. **Screen and refer** all HIV+ pregnant women to Healthy Start, regardless of score.
8. **Provide HIV testing** at jail entry, not just at release.



In March, 2008 the FIMR/HIV Case Review Team will begin selecting and reviewing cases again to monitor system changes and the impact of implementation activities.

HIV/FIMR Case Review Team

- Helen Jackson, Duval County Health Department, Chair
- Jackie Nash, First Coast AIDS Prevention Planning Com.
- Derya Williams, River Region Human Services
- Carol Synkewecz, Duval County Health Department, MCH
- Allison Dekle, Duval County Health Department, MCH
- David Andress, Duval County Health Department, HIV/AIDS
- Kathy Castro, Duval County Health Department, HIV/AIDS
- Dr. Isaac Delke, UF OB/GYN
- Dr. Mobeen Rathore, UF Rainbow Center
- Lori Bilello, Health Planning Council of NEF
- Curtis Montgomery, consumer
- Deidre Kelley, City of Jax, Ryan White Part A Planning Cncl.
- Pat Alexander, City of Jax, Ryan White Part A Planning Cncl.
- Willie Roberts, Shands Jacksonville
- Nicole Richardson, VOICES, Women’s Center of Jacksonville
- Laura Cubbedge, UF OB/GYN
- Jessica Joyce, UF Rainbow Center
- Faye Johnson, Azalea Project
- Carol Brady, NEF Healthy Start Coalition
- Laurie Lee, FIMR
- Dr. Katherine Huddleston, FIMR & UF/Shands

Next Steps

Preliminary recommendations from the Jacksonville FIMR/HIV Pilot Project will be presented to the Ryan White Part A Planning Council and the First Coast Community AIDS Prevention Partnership during the summer of 2007.

During 2007/08, the initial six months (September – February) will focus on the refinement, dissemination and implementation of preliminary recommendations.

The Jacksonville FIMR/HIV Pilot Project is funded through a contract from the University of Nebraska, Department of Pediatrics, CityMatCH.

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