



Charlie Crist  
Governor

Ana M. Viamonte Ros, M.D., M.P.H.  
State Surgeon General

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**Fetal and Infant Mortality Review  
Conference Call Minutes  
September 24, 2008**

**Next FIMR Call:**

December 17, 2008, 9:30 a.m. – 10:30 a.m. EST

**Toll-free number:** (888) 808-6959

**Conference Code:** 0281037

**Facilitator:** Louise B. Jones

**Recorder:** Julie Beaman

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**Attendees:**

<b>FIMR Sites and Support</b>	<b>Present</b>
Northeast Florida Healthy Start Coalition, Inc.	X
Bay, Franklin, Gulf Healthy Start Coalition, Inc.	X
Broward Healthy Start Coalition, Inc.	X
Chipola Healthy Start	X
Healthy Start Coalition of Miami-Dade, Inc.	X
Escambia County Healthy Start Coalition, Inc.	X
Healthy Start Coalition of Flagler and Volusia Counties, Inc.	X
Healthy Start Coalition of Hardee/Highlands/Polk Counties, Inc.	X
Capital Area Healthy Start Coalition, Inc.	X
Healthy Start Coalition of Pinellas County, Inc.	X
Healthy Start Coalition of Sarasota County, Inc.	X
Jason Stamm, BASINET Technical Assistance	X
Dani Noell, FIMR Technical Assistance	X

**Headquarter Attendees:** Maureen Ahearn, Julie Beaman, Cheryl Clark, Cynthia Coaxum, Felisha Dickey, Brandy Jones, Louise Jones, Chris LeClair, Mike Mason, Laura Pan, Susan Potts, Vivienne Treharne and Lynn Smith.

**Special Guests:** Nita Harrelle of the Department of Health Perinatal HIV Program. Broward County guests - representatives from Eligible Metro Area, Part A Ryan White Program and Part D Ryan White Program. Palm Beach guests - Ryan White Part A program.

## **Welcome- Louise Jones**

Louise Jones welcomed all to the quarterly Fetal and Infant Mortality Review (FIMR) conference call noting the National Healthy Start Association working with Congress has designated September 2008 as Infant Mortality Awareness Month. Louise introduced Laurie Lee, FIMR coordinator for the Northeast Florida Healthy Start Coalition, Inc.

### **1. Jacksonville FIMR/HIV Pilot Project – Laurie Lee**

Laurie Lee presented an overview of the Jacksonville FIMR/HIV Pilot Project. This project was made possible by a grant from the Center for Disease Control, CityMatCH, and the National Fetal Infant Mortality Review (NFIMR) Committee. Ms. Lee reported that the group reviewed thirty two files using a modified version of the FIMR process to examine pregnancies of HIV positive women. The cases reviewed were based on several key factors such as timing of woman's diagnosis of HIV, pregnancy outcomes and other factors. For a complete description of the project and the findings, please see the attached power point and report.

#### Questions and Comments -

**Comment:** Nita Harrelle, DOH, Division of HIV thanked Ms. Lee for her wonderful presentation. Ms. Harrelle added that twenty percent of HIV positive moms were infected while they were pregnant. She stated that they know this because the women tested negative at initial diagnosis of pregnancy. She stressed the importance of educating women on family planning.

**Question:** A representative from Broward County asked how the department is tracking HIV infected infants. The representative stated they did not feel that the current data shown is accurate for Broward.

**Answer:** Nita Harrelle responded that it was only in 2006 that it became mandatory for HIV exposed infants to be reported. Ms. Harrelle stated that the department is diligently working on educating the medical community of this fairly new requirement in order to obtain accurate numbers.

**Question:** Another representative from Broward asked what the lag time is for reporting HIV exposed infants and publishing current data on these numbers. This representative stated that his unofficial tracking for Broward County shows currently 49 HIV exposed infants in Broward. Broward has developed a fact sheet regarding HIV exposed infants and has been working to educate their medical community about the requirement to now report these numbers.

**Answer:** Ms. Harrelle stated that she would have to research this question.

**Question:** Another guest asked Ms. Lee if funding for this initiative would be expanded and what their project cost.

**Answer:** Ms. Lee stated that she knew that expanding the program was the intent of the funders. However, she is unsure when this may happen. Also, Ms. Lee stated that she would check on the cost of their project.

Please see attached email for updated information regarding future funding and the amount of the pilot funding.

## **2. BASINET Update - Jason Stamm**

Jason announced the administration of the BASINET program is being taken over by GoBeyond, LLC. This should not affect users.

## **3. FIMR Process – Dani Noell**

Dani reminded everyone that NFIMR, [www.nfimr.org](http://www.nfimr.org), is a great resource for free materials and also a great source for exploring funding opportunities. Also, there are sample job descriptions for abstractors.

Dani also announced that PAMR is looking for abstractors. If anyone is interested, please contact Debbie Burch at [Deborah\\_Burch@doh.state.fl.us](mailto:Deborah_Burch@doh.state.fl.us).

**Question:** Some asked if other FIMR projects around the state were having any difficulty accessing infant death information.

**Answer:** Dani stated that sometimes we have to remind medical examiners of the FIMR program and its authority to review the infant death records.

JB/dm

## 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 cases. There were 249 AIDS cases (27.6 per 100,000 residents) and 346 HIV cases (38.3 per 100,000) reported in the county in 2007. 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 2005-2007.**

County	Total Births	HIV Infected Births	Rate/100,000 Births
DUVAL	40,339	4	9.9
Statewide	701,197	40	5.7

Source: Florida Department of Health, 2008.

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 32 cases were selected for detailed examination in 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 30 percent 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. Finally, the team reviewed aggregate findings on the 32 cases and developed ten recommendations for community action.

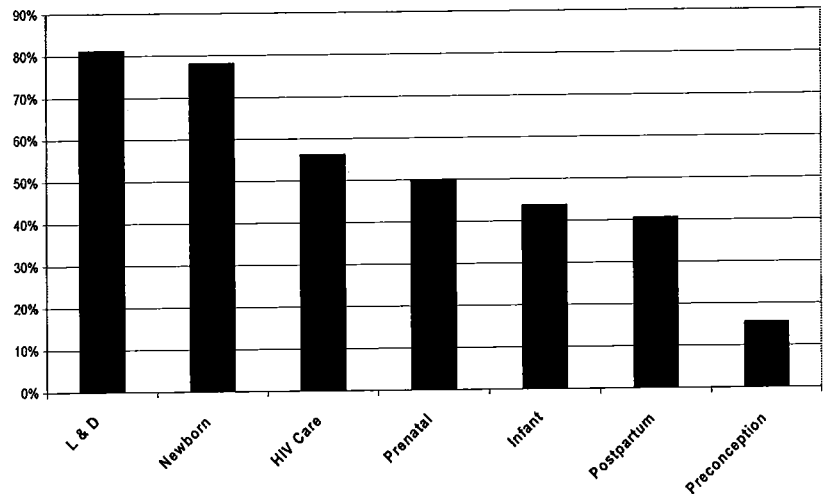
Findings and recommendations were presented to the Ryan White Part A Planning Council and the First Coast AIDS Prevention Partnership which served as the community action group. Case review team members also took the lead in responding to key recommendations.

### Birth Outcomes, Strengths & Contributing Factors

One of the cases reviewed resulted an infected infant. Two of the 32 cases resulted in a fetal loss including one where the mother died from AIDS at delivery. The 30 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 services in labor and delivery. A majority of cases received comprehensive newborn services, HIV care and prenatal services.

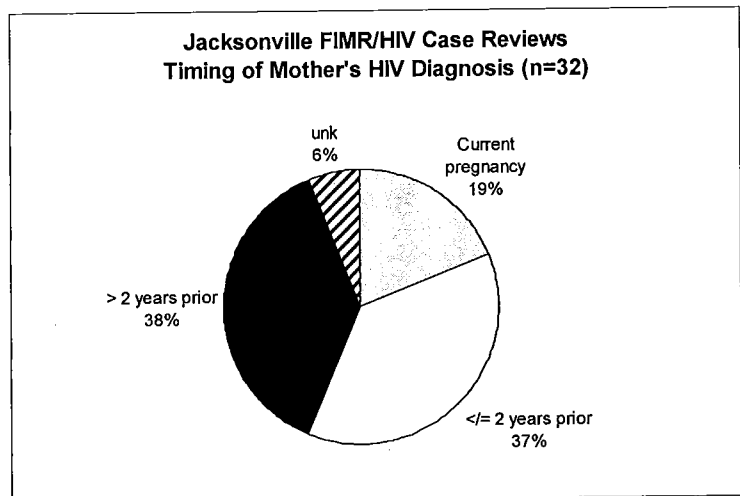
Jacksonville FIMR/HIV Pilot  
% of Cases Receiving Full Array of Services (n=32)



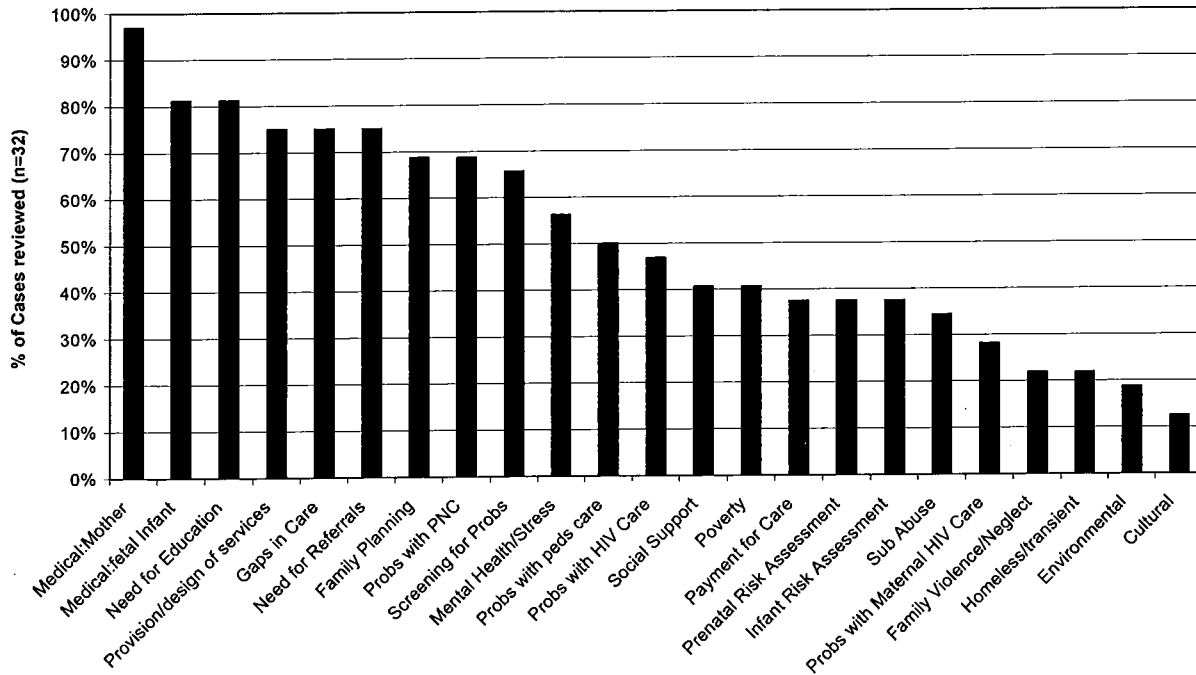
The majority of cases reviewed for the pilot project involved HIV+ mothers who were Black, age 20-25 years old, and single. Nearly 30 percent of the women received late or no prenatal care. A similar proportion entered care in the first trimester of pregnancy. Most of their care was paid for by Medicaid.

In 13 percent of the cases reviewed, this was the woman's first pregnancy; in more than half of the cases the woman had 1-2 previous pregnancies. Most of the women knew their HIV status prior to the pregnancy reviewed. Less than 20 percent were diagnosed in the current pregnancy; nearly 40 percent had been diagnosed more than two years prior.

Jacksonville FIMR/HIV Case Reviews  
Timing of Mother's HIV Diagnosis (n=32)



**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-seven percent of the cases involved some maternal medical problem, such as infection, obesity or poor nutrition. In over 80 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 safer sex, family planning and birth spacing, and medication compliance was identified as an issue in more than 80 percent of the cases reviewed.

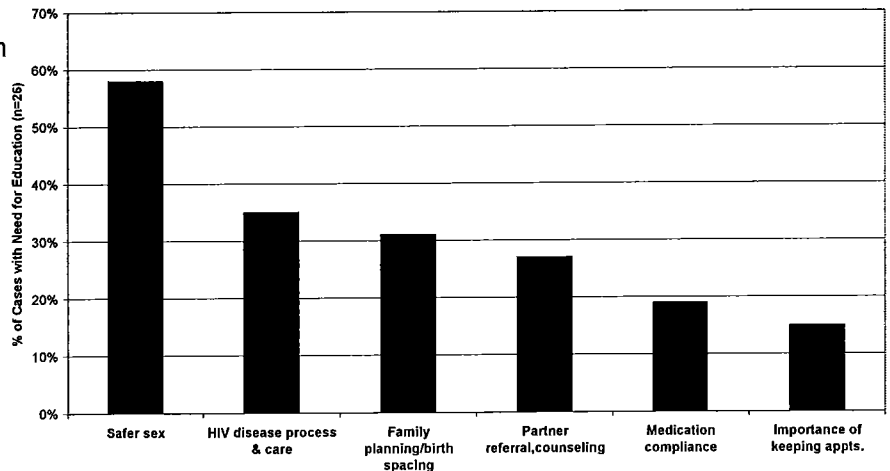
Issues were identified with the design and delivery of services in about 75 percent of the cases reviewed. Included in this category were patient dissatisfaction with services and communication problems between providers and between patients and providers.

In about 75 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 in this category.

The need for referrals to mental health services, Healthy Start and/or WIC was identified in 24 of the 32 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. More than half of the cases involved unintended or unplanned pregnancies. No contraceptive method was being used in nearly one-third of the cases examined.

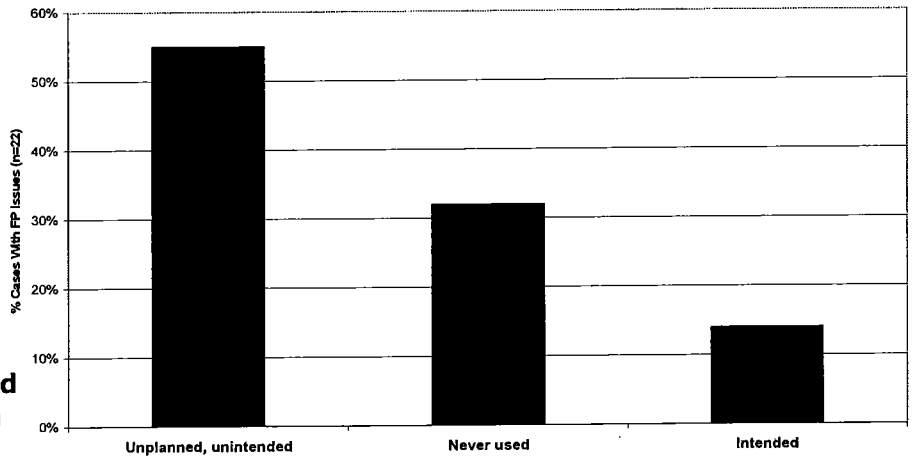
**Jacksonville FIMR/HIV Pilot  
Need for Education  
Most Frequent Problems Identified**



**Recommendations**

Based on the review of 32 cases, the FIMR/HIV case review team adopted these 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, safer sex education and partner referrals** for HIV+ women of childbearing age.
3. **Create an interagency HIV case management task force.**
4. **Ensure the timely transfer** of records between providers through interagency agreements.
5. **Increase Ryan White funding for mental health & community counseling services.**
6. **Screen and refer** all HIV+ pregnant women to Healthy Start, regardless of score.
7. **Provide HIV testing** at jail entry, and increase linkages with HIV providers in the community.
8. **Provide access to local HIV specialty care** through Medicaid and all insurance plans.
9. **Increase funding for medical nutrition therapy** to address co-morbidities that impact outcomes.
10. **Utilize every opportunity to re-engage** and link HIV-infected women using specific protocols for all providers who come into contact with them.



formed to share information and ensure all HIV+ pregnant women were assigned to a case manager. And, the Ryan White Part A Planning Council incorporated strategies in its updated plan for improving the integration of HIV care, GYN and family planning services through its case management programs. The Coalition is working with the state on possible replication of the FIMR/HIV project in other Florida communities. Additional reviews, focusing on cases where perinatal HIV transmission has occurred, are planned.

**HIV/FIMR Case Review Team**

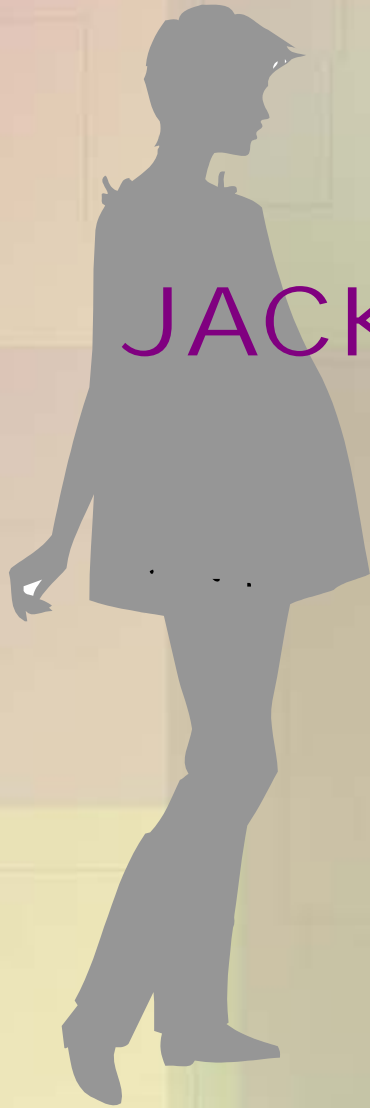
- Helen Jackson, Duval County Health Department, Chair
- Jackie Nash, First Coast AIDS Prevention Planning Com.
- Derya Williams, River Region Human Services
- Carol Synkewecz, Duval County Health Department, MCH
- David Andress, Duval County Health Department, HIV/AIDS
- Dr. Max Wilson, Duval County 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.
- Dr. Graham Watson, City of Jax, Ryan White Part A Cncl.
- Willie Roberts, Shands Jacksonville
- Sharon Lutheran, WIC & Nutrition
- Nicole Richardson, VOICES, Women's Center of Jacksonville
- Christopher Pratt, Duval Co. Health Dept, FP/HIV Integration
- Jessica Joyce Long, UF Rainbow Center
- Faye Johnson, Azalea Project
- Carol Brady, NEF Healthy Start Coalition
- Laurie Lee, FIMR
- Dr. Katherine Huddleston, FIMR & UF/Shands

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

For more information, contact Carol Brady, Executive Director, Northeast Florida Healthy Start Coalition  
 904-723-5422 ext 111 [cbrady@nefhsc.org](mailto:cbrady@nefhsc.org)  
[www.nefhealthystart.org](http://www.nefhealthystart.org)

**Implementation Success**

Three significant implementation efforts were initiated as a result of project activities. The Duval County Health Department successfully applied for special Title X funding to promote HIV testing and improve service integration in family planning clinics. An interagency group of case managers was



# JACKSONVILLE FIMR/HIV Pilot Project

Adapting FIMR to Examine the  
Pregnancies of HIV+ Women

**DOH FIMR Quarterly  
Conference Call  
September, 2008**

# HIV in Jacksonville

- Jacksonville-Duval County ranks sixth statewide in reported HIV/AIDS cases.
- 41% of HIV cases since 1997 were women
- 1 in every 90 Black women in city is living with HIV/AIDS
- Heterosexual contact leading mode of transmission
- Nearly 80 HIV-infected women a year become pregnant in Jacksonville

# Perinatal HIV Infected Babies By County, 2005-2007

County	Total Births	HIV Infected Births	Rate/100,000 Births
Broward	69,423	8	11.5
Dade	100,341	8	8.0
<b>DUVAL</b>	<b>40,339</b>	<b>4</b>	<b>9.9</b>
Dixie	539	1	185.5
Indian River	4,184	1	23.9
Marion	10,729	1	9.3
Orange	50,321	4	7.9
Palm Beach	46,524	6	12.9
Pinellas	27,932	2	7.2
St. Lucie	10,147	3	29.6
Volusia	15,740	2	12.7
Statewide	701,197	40	5.7

Source: Florida Department of Health, 2008.

# FIMR/HIV Pilot

- In 2005, Jacksonville, two other cities selected by CDC, CityMatCH and NFIMR to pilot use of FIMR process in examining the experiences of HIV+ women and their families in and around pregnancy.
- Goal: to review, identify, address and reduce missed opportunities for providing optimum care to HIV+ pregnant women and preventing mother-to-child HIV transmission.

# Jacksonville Project Partners

- NEF Healthy Start Coalition
- UF Rainbow Center (Ryan White Part C, D)
- Duval County Health Department
- Florida Department of Health- HIV/AIDS (Ryan White Part B)
- City of Jacksonville (Ryan White Part A)
- First Coast Community AIDS Prevention Partnership
- Other Community MCH, HIV/AIDS Groups



# Overview of Review Process

- **Case identification & selection**
  - Purposeful, not random selection
  - Cases selected based on some indication of system gap:
    - Timing of the woman's diagnosis
    - Pregnancy outcome
    - Entry into prenatal care
    - Mother's HIV treatment status and viral load
    - Mother's receipt of antiretroviral prophylaxis during labor and delivery
  - 32 cases reviewed



# Overview (con't)

- **Case Abstraction**

- Contract with UF Rainbow Center
- All available medical, hospital, CM records
- Info collected: prenatal care, labor and delivery care, post-partum/reproductive health care, maternal HIV care, newborn care, and pediatric care.
- De-identified

- **Maternal interview**

- Social worker at Rainbow Center
- Completed on about 30% of cases reviewed



# Overview (con't)

- **Case Review**

- Multidisciplinary team (MCH, HIV/AIDS, community)
- Monthly case reviews (starting Feb. 2007)
- Strengths, opportunities for improvements, issues identified
- Recommendations



# Overview (con't)

- **Community Action**

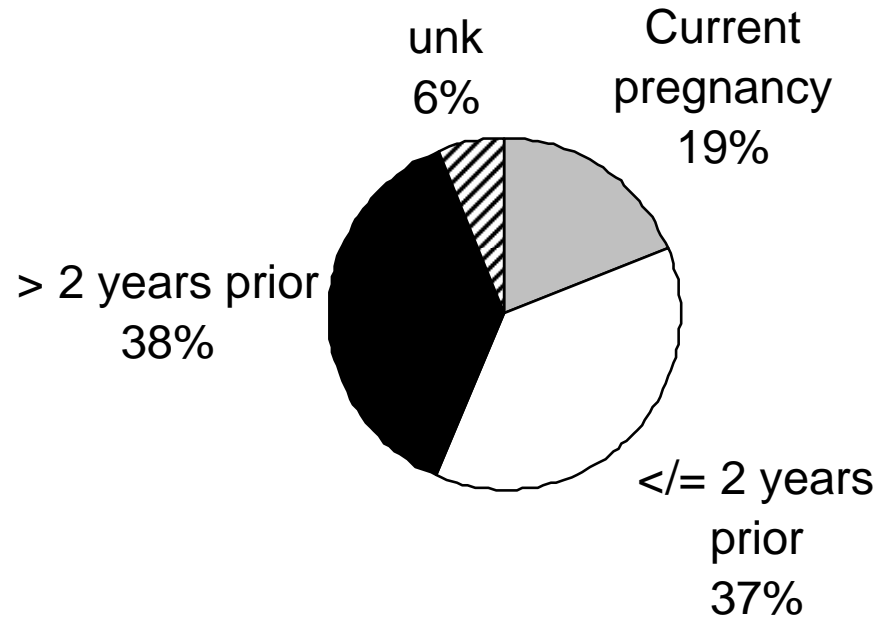
- Role: Initiate systems change based on findings, recommendations
- “Champions”
  - UF Rainbow Center
  - Duval County Health Department
  - Ryan White Part A Planning Council
  - First Coast Community AIDS Prevention Partnership
  - Case Review Team Oversight

# Profile of Cases Reviewed

- Most cases 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.
- About same proportion started care in first trimester
- Most of their care was paid for by Medicaid.
- In 13 percent of the cases, this was the woman's first pregnancy

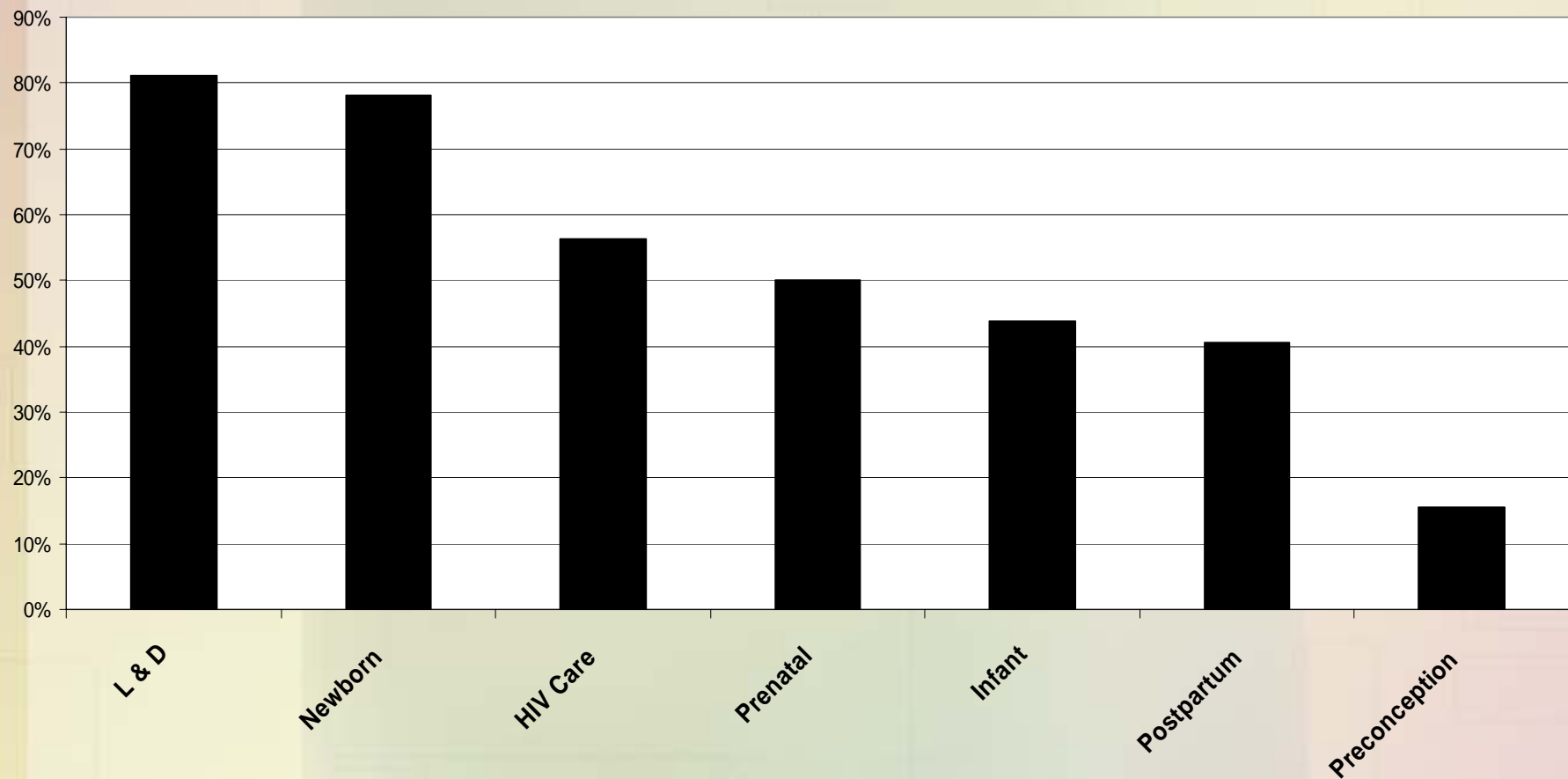


## Jacksonville FIMR/HIV Case Reviews Timing of Mother's HIV Diagnosis (n=32)



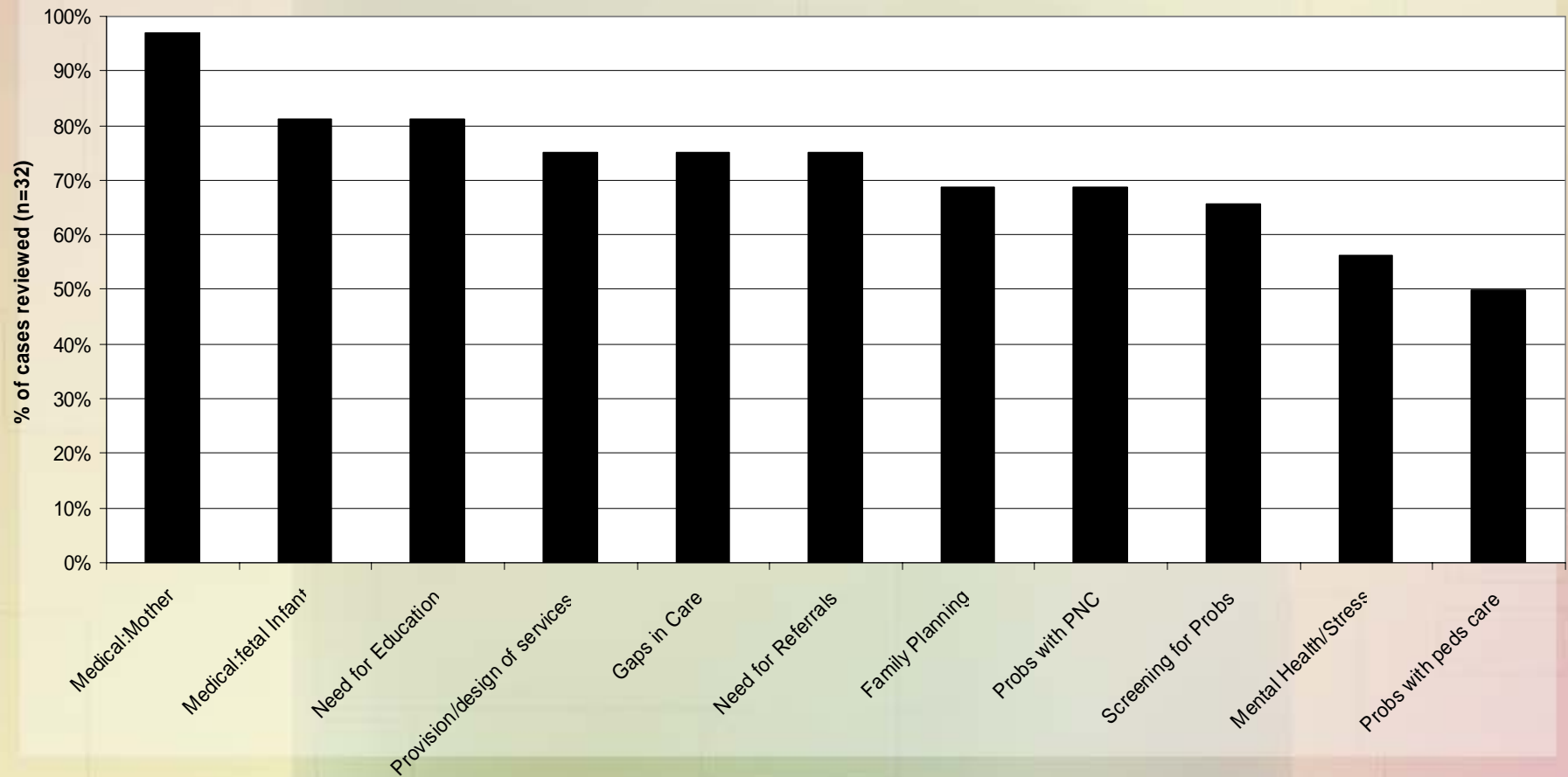
# Preliminary Findings: Strengths

Jacksonville FIMR/HIV Pilot  
% of Cases Receiving Full Array of Services (n=32)



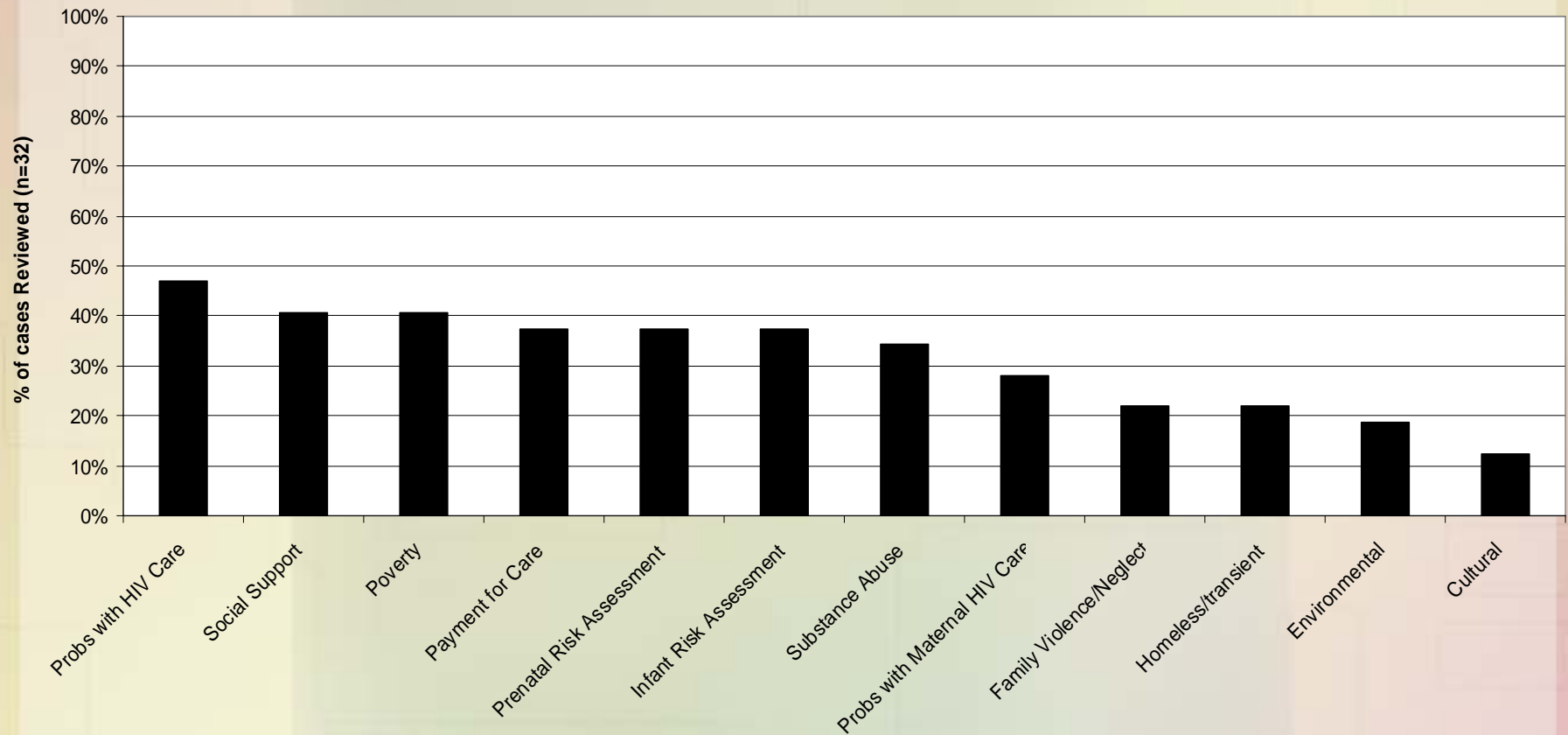
# Preliminary Findings: Concerns

Jacksonville FIMR/HIV Pilot  
Frequency of Issues Identified



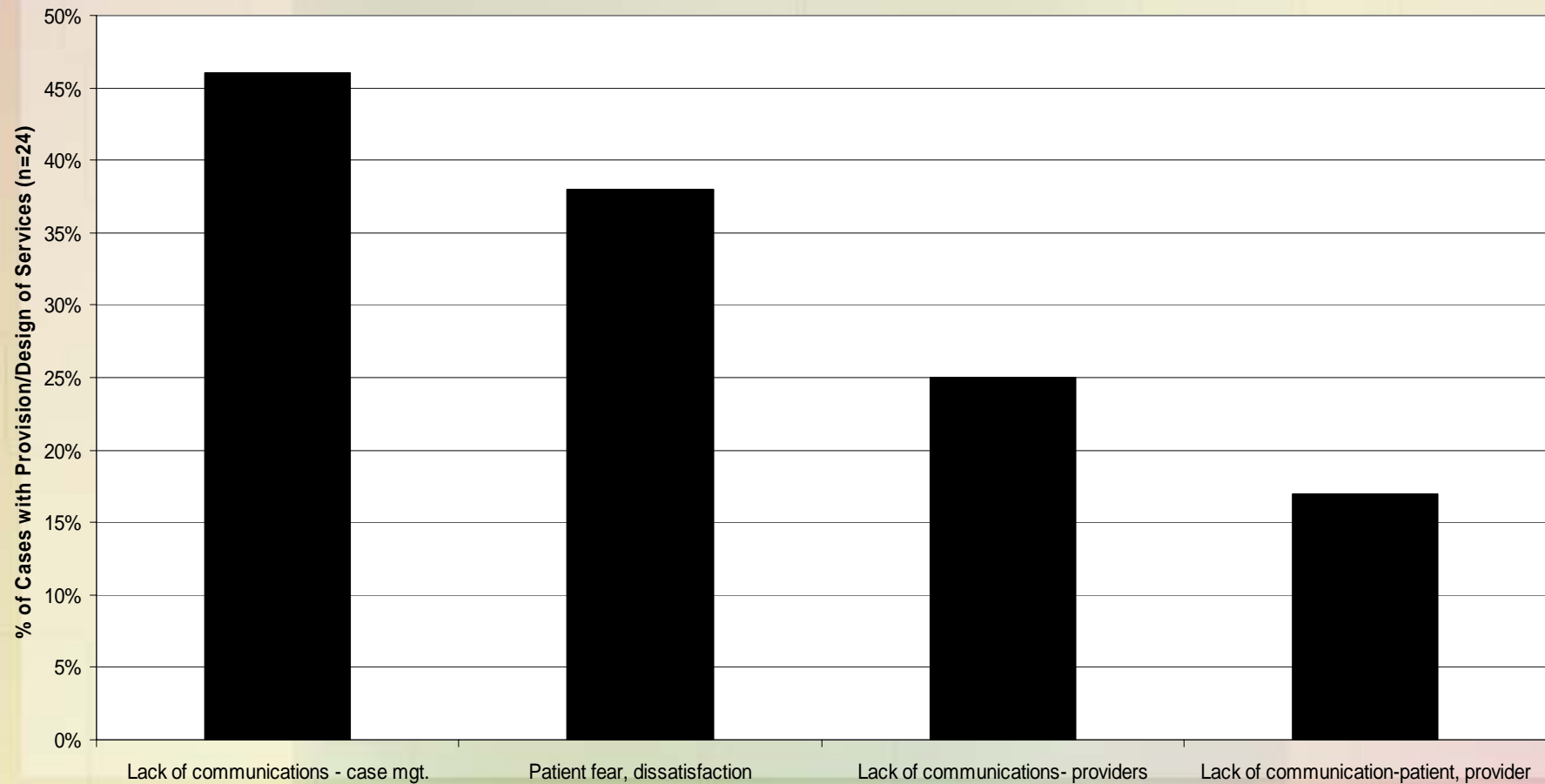
# Preliminary Findings: Concerns

Jacksonville FIMR/HIV Pilot  
Frequency of Issues Identified (con't)



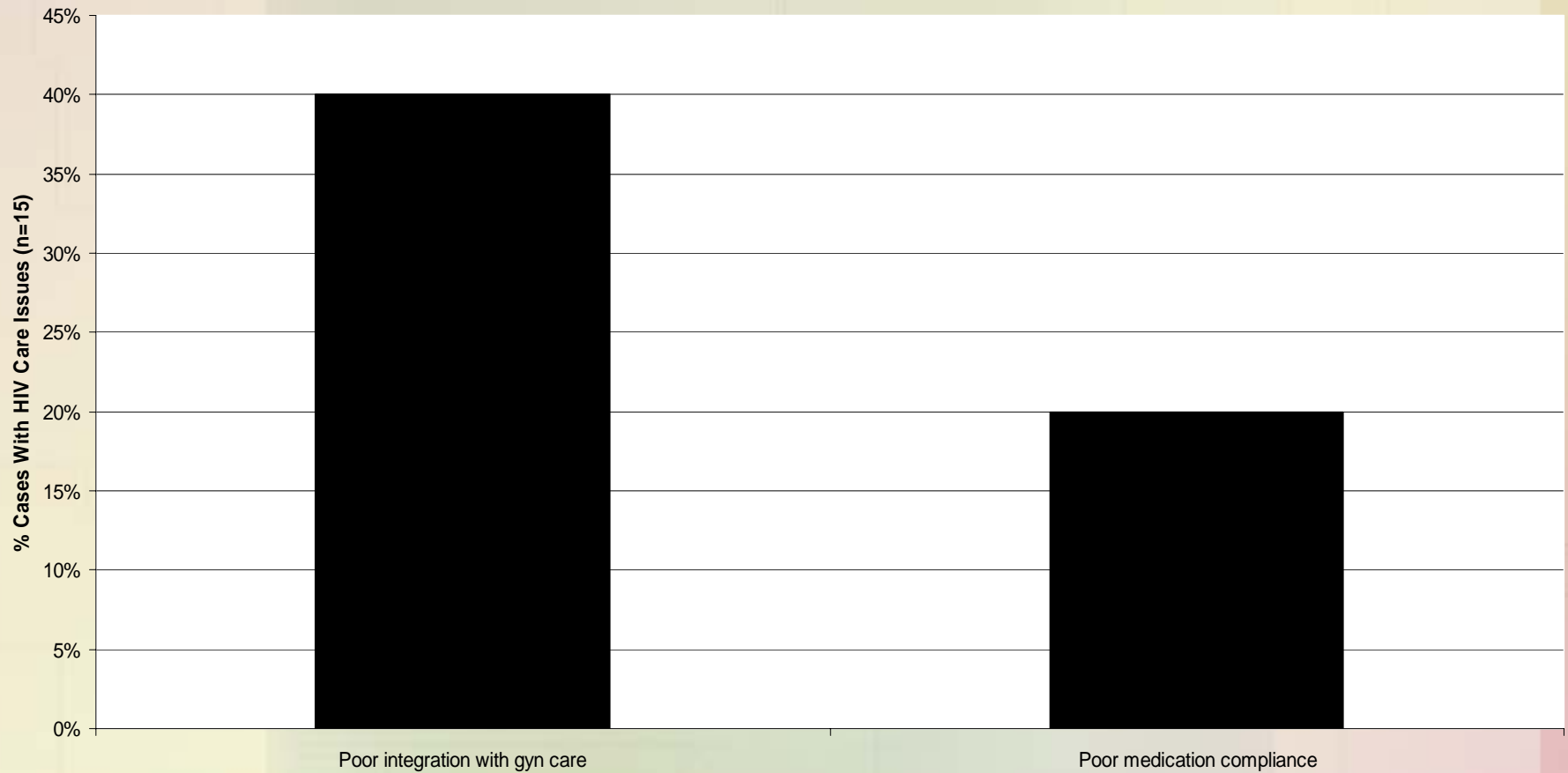
# Preliminary Findings: Concerns

Jacksonville FIMR/HIV Pilot  
Provision/Design of Services  
Most Frequent Problems Identified



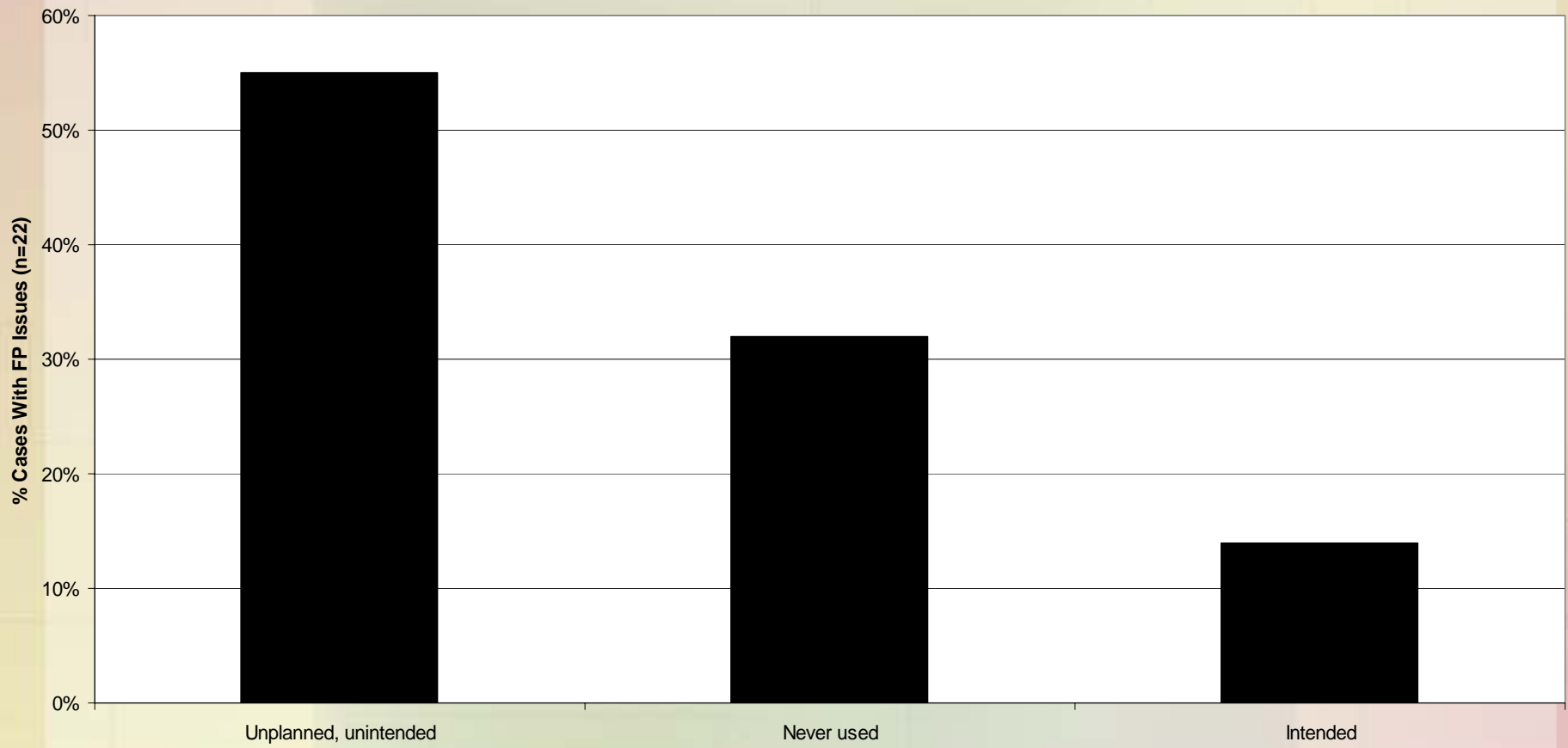
# Preliminary Findings: Concerns

Jacksonville FIMR/HIV Pilot Project  
HIV Care Issues  
Most Frequent Problems Identified



# Preliminary Findings: Concerns

Jacksonville FIMR/HIV Pilot  
Family Planning Issues  
Most Frequent Problems Identified



# Recommendations

- 10 recommendations
- **“Themes”**
  - Need to **integrate** HIV/Reproductive Health Services
  - Need to take advantage of missed opportunities for **re-engaging** HIV+ women lost to care
  - Need for improved service **coordination**
  - Need to reduce **barriers** to services

# From Reviews to Action!

- Work group established at Shands-Jax to ensure all pregnant women at high-risk clinic receive case management
- Health Dept successfully funded for Title X grant to increase testing, integrate HIV & FP services
- Ryan White Part A Assessment & Screening revisions under development (goal: integration of HIV, reproductive health care)
- Changes to internal processes (UF Rainbow)
- Grand rounds, presentations

# Factors Contributing to Success

- Jacksonville's history of strong collaboration
- CRT: diverse, committed group
- Leadership and staff of UF Rainbow Center
- Coalition's FIMR experience



# Challenges

- Resources
- Super-confidentiality of HIV data
- IRB
- Redundancy, organization of forms

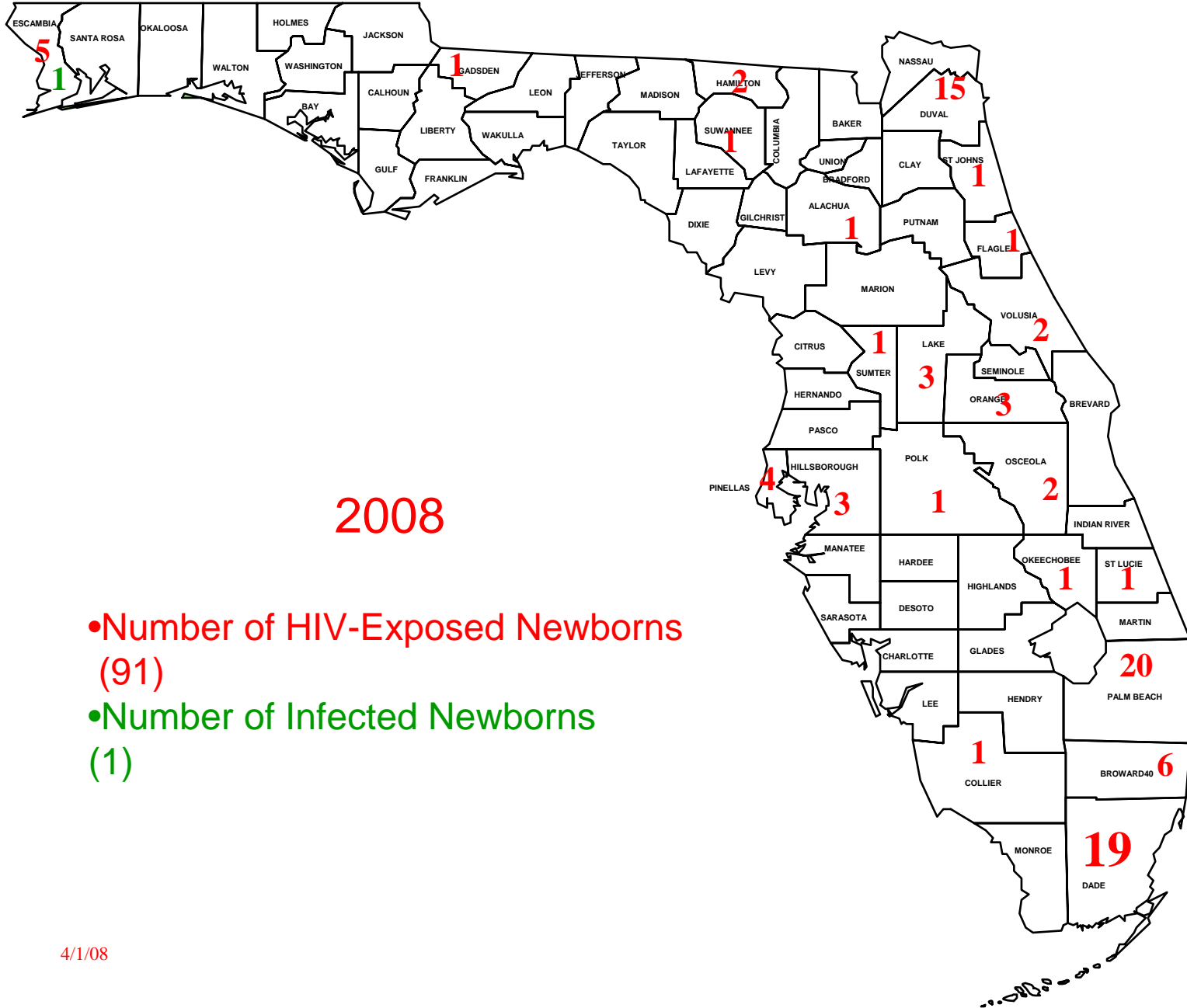


# Sustainability

- CRT agreed to meet quarterly after pilot
  - Monitoring, promoting implementation of recommendations
  - Review of all cases that result in perinatal HIV transmission (if resources can be identified)
- Advocacy on state, local level (Title V, HIV/AIDS) for continued resources

# Opportunities!

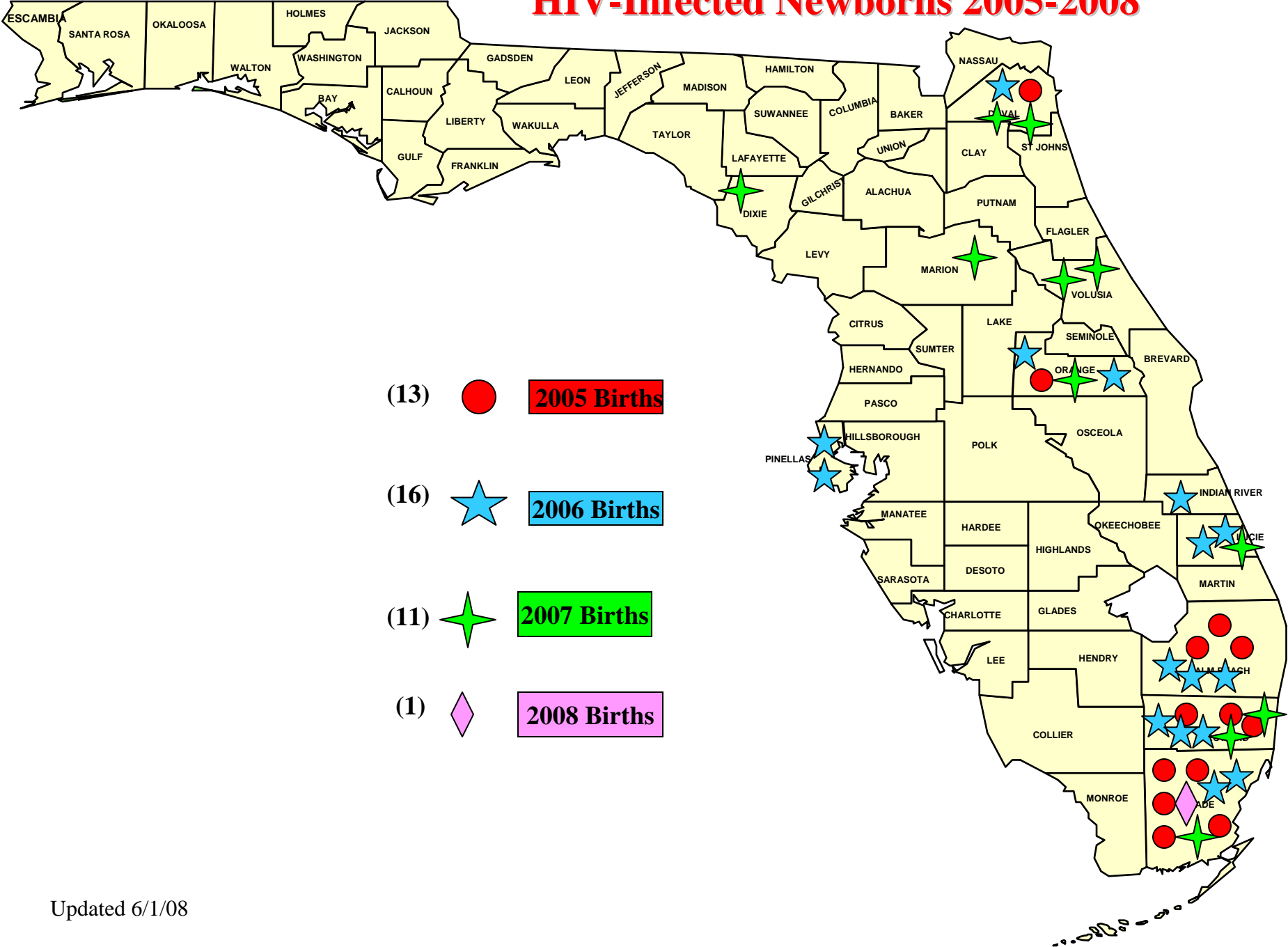
- Potential for replication in other parts of the state?
- Questions? Thanks!
- For more information: Carol Brady  
[cbrady@nefhsc.org](mailto:cbrady@nefhsc.org)



2008

- Number of HIV-Exposed Newborns (91)
- Number of Infected Newborns (1)

# HIV-Infected Newborns 2005-2008



(13) ● 2005 Births

(16) ★ 2006 Births

(11) ☆ 2007 Births

(1) ◆ 2008 Births