Creating a Safety Net for HIV Exposed Infants in Illinois

Perinatal HIV Elimination Project

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The Safety Net

- Perinatal Rapid Testing Initiative
- Enhanced Case Management
- 24/7 Perinatal HIV Hotline
HIV in Illinois

- Seroprevalence of HIV in Illinois is 0.1%
- Higher seroprevalence has been noted in:
  - Chicago 0.3%
  - Cook County 0.2%
  - East St. Louis area 0.2%.
In 2000 the Pediatric AIDS Chicago Prevention Initiative (PACPI) was created to help eradicate the transmission of HIV from mother to child in Chicago.

In 2003 the Perinatal Rapid HIV Testing Implementation Initiative (PRTII) was created to find the women who presented late in pregnancy.

In 2003 the 24/7 Perinatal HIV Hotline was created to help link hard-to-reach women to care and to provide real-time medical consultation on HIV-related obstetric and pediatric issues.
Accomplishments

**PACPI** has case managed 188 women (202 pregnancies) since 2002
- 4 cases of perinatal transmission have occurred (two cases prior to linkage with services) within the PACPI cohort

**PRTII** has identified 69 HIV positive women since November 2004
- 5 cases of perinatal transmission have occurred among women identified through rapid testing on L&D

**24/7 Hotline** has received 237 calls from 1/04-9/07
- 105 unlinked pregnant HIV+ women were identified
  - 83 were linked to medical care
  - 71 were linked to enhanced case management
Case Study

- 23 y.o. NHB female G4 P1 who presented with symptoms of labor.
- No prenatal record was available upon admission, so client was counseled, consented and a rapid test was administered.
- Client had a history of injection drug use and was receiving methadone in an outpatient program.
- Client likely had been tested for HIV prior to the rapid test, but was in deep denial about her status and not compliant with care.
- Mother and baby were discharged home with seven days of AZT syrup for the baby.
Hotline Involvement in the Case

- The hospital called the 24/7 Perinatal HIV Hotline to report the preliminary positive result.
- Hotline staff verified the treatment of the mother (IV AZT) and baby (AZT syrup and Nevirapine).
- Hotline staff recommended the client be linked with a PACPI enhanced case manager and faxed a release of information form.
- Client signed the Hotline release of information, and the case manager visited the hospital later that same day.
24/7 Perinatal HIV Hotline

- Provide real-time medical information on HIV related obstetric and pediatric issues.
- Link HIV-positive mothers and infants to medical care and case management during and after pregnancy.
- Act as a reporting mechanism for positive rapid HIV tests and provide post-test counseling and linkage to care for mothers and exposed infants with positive rapid tests.
Case Study - continued

- The case manager educated the client about HIV and what to expect. The client did not seem to be shocked by the news of her preliminary status.

- Client did not attend her postpartum visit, missed the first pediatric visit for the baby and was initially resistant to case management and home visits.

- Baby developed a fever at 21 days and was brought in by the client to the emergency room; at this time the mother disclosed the possible HIV exposure to the staff.

- The Department of Children and Family Services conducted an investigation of the family and the mother was allowed to retain custody.
Enhanced Case Management
Involvement in the Case

- Permanent housing (client previously living with family)
- Starter cell phone with minutes
- Assistance with transportation to maternal and pediatric appointments
- Safety in the home with a new infant
- Parenting classes
Case management is a field-based service focusing on the hardest-to-reach, hardest-to-link women experiencing the following:

- homelessness
- domestic and community violence
- mental illness
- depression
- chemical dependency
- involvement with child welfare services
- arrest and incarceration
- legal status issues
- poverty

We also serve clients who are refugees/asylees, non-English speaking and multiply diagnosed.
Rapid Testing
Involvement in the Case

- Labor and delivery staff performed a rapid test on the woman who presented with no documented HIV status.

- Rapid results were available from the lab in 50 minutes and communicated to the patient by the physician handling the case.

- The 24/7 Perinatal HIV Hotline was called per protocol and the preliminary positive data form was completed and faxed to PRTII.
Case Study Hospital: Rapid Testing Performance

- This particular hospital has a 7.2% undocumented HIV test rate at presentation (Q3 2007)
- Initial rapid testing rate: 97.1% in 2005 (Q4)
- Current rapid testing rate: 100% in 2007 (all quarters)
- Perinatal Network Stats:
  - 11.4% undocumented HIV status at presentation
  - 99.1% of women accept RT at L&D
  - 100% of mother/baby pairs discharged with HIV status (Q3 2007)
PRTII Mission Statement

To implement Rapid HIV Testing in every L&D unit in Illinois by June 2005 to reduce perinatal HIV transmission and prevent pediatric HIV in Illinois
PRTII Rationale

- **Opportunity**
  - New Illinois law
  - FDA approved Rapid HIV Test

- **Need**
  - Incomplete prenatal testing
  - Unknown maternal HIV status = preventable pediatric HIV

- **Intervention**
  - If maternal HIV status known = effective treatment on labor & delivery to prevent perinatal transmission

- **Goal**
  - Eliminate Pediatric HIV in Illinois
An Opportunity: Illinois Perinatal HIV Prevention Act

- **All pregnant women** in Illinois will be counseled and offered an HIV test.

- **HIV test results will be documented** in prenatal, L&D and newborn pediatric chart.

- **If there is no documented** maternal HIV status on arrival to L&D, the patient **will be offered a Rapid HIV test.** (Opt-In)

- **If maternal status not known at delivery,** newborn will be given rapid HIV test. (Opt-Out 6/05, Mandatory as of 6/06)
Case Study - Outcome

- Client agreed to case management services and home visits by the case manager
- Mother and baby remain linked to care at six months postpartum
- Client has retained custody of the infant
- Client continues to receive outpatient methadone
- Infant has a **negative PCR** at 4 months of age
24/7 Perinatal HIV Hotline Data
Reason for Call (1/2004-9/2007)*

*Data are not mutually exclusive
Referral Sources (N=237 calls)

- Hospital L&D: 54.9%
- OB Clinic: 13.5%
- Hospital Other Dept.: 11.4%
- Dept of Health: 3.0%
- Hospital ED: 1.3%
- Private Provider: 0.8%
- Social Service Agency: 0.8%
- Self Referral: 14.3%

Total: 100.0%
Pregnancy Status at Time of Call (N=237 calls)

- Antepartum: 39.7%
- Intrapartum: 14.8%
- Postpartum (in hospital): 21.9%
- Postpartum (remote): 9.7%
- Non-pregnant: 13.9%
Care Status of Pregnant Women - Positive and Preliminary Positive - at Time of Identification (N=158 cases)

- No Care: 81 cases
- Some Prenatal Care - No HIV Care: 42 cases
- Linked to Care: 28 cases
- Unknown: 7 cases
Linkage to Medical Care for Unlinked Pregnant HIV+ Women (N=105)

- Linked to Care: 51
  - Postpartum HIV Care: 32
  - Prenatal HIV/OB Care: 19

- Not linked to care: 4
Timing of Calls and Referral to Enhanced Case Management for Linkage to Care (N=105)

- Real-time: 68 referred, 21 not referred
- Retrospective: 3 referred, 13 not referred
HIV Status of Perinatally Exposed Infants Identified to Hotline (N=100)

- Positive: 6
- Negative: 70
- Negative Testing to Date: 15
- No Info Available: 9
Enhanced Case Management Data
Enhanced Case Management: Model

- Intensive model targeted to hard-to-reach, hard-to-link women
- Field-based model including home visits
- Targeted around the pregnancy and postpartum period
- Small caseloads
- Connected to the Hotline and Rapid Testing follow up
Enhanced Case Management: Direct Referrals

- Northeastern Illinois Case Management Cooperative
- Specialty HIV/OB programs
- Social service programs (chemical dependency treatment, child welfare, shelters, housing agencies, health dept)
- Previous clients
Enhanced Case Management: Methods

- Escort to appointments
- Family counseling/education
- Assistance with benefits, referrals
- Emergency assistance (housing, utilities)
- Transportation (rides, public transit, taxi)
- Social and emotional support
- Coordination with other case managers (child welfare, mental health, housing)
- Observation of AZT administration in home
Who are the case managers?

- Experienced case managers
- Specialty experience in at least one field (adolescents, housing, substance abuse, domestic violence)
- Younger, approachable women who are also mothers
- Specialty training in perinatal HIV treatment and issues
Enhanced Case Management: Demographics

- Average age of clients: 27 years
- Average age at first pregnancy: 16.5
- Race:
  - 73.4% NHB
  - 17% H
  - 5.3% NHW
  - 4.3% Other/Unknown
Enhanced Case Management: HIV Status

- 47% of women diagnosed with HIV in current pregnancy
- 11% of women have an AIDS diagnosis
Enhanced Case Management: Insurance Status

- 63.3% Medicaid
- 15.4% Uninsured
- 11.7% Medicare
- 5.3% Unreported
- 2.7% Private
- 1.6% Other/other public
One case of transmission from 2001-2006 (City of Chicago recorded 19 other cases of transmission in the same period)

All clients connected with prenatal care, ID care and pediatric ID for exposed newborns

CDC cost effectiveness and outcomes evaluation of perinatal enhanced case management (8/06 – 8/08)
Enhanced Case Management: Future Plans

- Standardization of perinatal case management protocol for the state
- Perinatal case management training (Ryan White Part A, B and C) and certification
- Publicize results of the case management evaluation
- Expansion across the state to other metro areas
Rapid HIV Testing Data
Illinois Birthing Hospitals
January - December 2005
as of 5/30/06

Documented

- Delivering pts: 141,773
- Women: 16,575 (11.7%)
  - Missed: 439 (2.6%)
  - Declined: 4,470 (26.9%)
  - Tested: 11,625 (70.1%)

Undocumented Babies: 4,135

- No refusal: 659 (15.9%)
- Refused: 3,227 (78.0%)
- Tested: 242 (5.9%)

Babies discharged without HIV status: 3,886

Documentation at discharge: 97.3%

An additional three true positives (and one false positive) identified in outpatients on L&D

- TruePos: 20
- FalsePos: 7
- Neg: 11,595

125,198 (88.3%)
125,067
131

125,198
125,067
131

439 (2.6%)
4,470 (26.9%)
11,625 (70.1%)

4,135

659 (15.9%)
3,227 (78.0%)
242 (5.9%)

Babies discharged without HIV status: 3,886

141,773
11,625
11,595

11,625
11,595
11,595
### Illinois Hospitals

**January – December 06**  
as of 02/01/07

<table>
<thead>
<tr>
<th>Group</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivering pts</td>
<td>175,248</td>
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<tr>
<td>Documented</td>
<td>162,329</td>
<td>92.6%</td>
</tr>
<tr>
<td>Undocumented Women</td>
<td>12,909</td>
<td>7.4%</td>
</tr>
<tr>
<td>Missed</td>
<td>92</td>
<td>0.7%</td>
</tr>
<tr>
<td>Declined</td>
<td>1,849</td>
<td>14.3%</td>
</tr>
<tr>
<td>Tested</td>
<td>10,979</td>
<td>85.0%</td>
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<tr>
<td>Maternal doc Postpartum</td>
<td>17</td>
<td>0.8%</td>
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<tr>
<td>No refusal Untested</td>
<td>119</td>
<td>6.2%</td>
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<tr>
<td>Refused Untested</td>
<td>1,616</td>
<td>83.9%</td>
</tr>
<tr>
<td>Tested</td>
<td>175</td>
<td>9.1%</td>
</tr>
<tr>
<td>Babies discharged w/o HIV status</td>
<td>1,735</td>
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<tr>
<td>Fetal demise/ IUFD</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Babies discharged w/o HIV status</td>
<td>1,735</td>
<td></td>
</tr>
<tr>
<td>Documentation at discharge: 99.0%</td>
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<td></td>
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</tbody>
</table>

An additional nine true positives (and four false positives) identified in outpatients on L&D.
Illinois Birthing Hospitals

January – September 07
as of 11/15/07

Delivering pts
132,185

Documented
124,066 (93.9%)

Pos 113

Neg 123,953

Undocumented Women
8,119 (6.1%)

Missed
52 (0.6%)

Declined
96 (1.2%)

Tested
7,972 (98.2%)

Undocumented Babies
140

Fetal demise/ IUFD
15

Maternal RT post-partum
15 (10.7%)

No refusal
Untested
20 (14.3%)

Refused
Untested
13 (9.3%)

Tested
92 (65.7%)

Babies discharged w/o HIV status
33

An additional six true positives (and two false positives) identified as outpatients

TruePos 14
FalsePos 2

Prelim Pos 16
Neg 7,956

TruePos 1
FalsePos 0

Neg 91

Documentation at discharge: 99.96%
IDPH Performance Standards and September 07 results

Documentation at presentation
- Minimal acceptable rate of documentation 80% - Target documentation rate 95%  \((\text{Sept} = 93.9\%)\)

Acceptance of rapid testing at delivery
- Minimum acceptable testing acceptance 89% - Target rate 95%  \((\text{Sept} = 98.8\%)\)

Decline rate for testing
- Minimum acceptable decline rate 10% - Target decline rate 5%  \((\text{Sept} = 0.3\%)\)

Women missed for rapid testing at labor and delivery
- Minimum acceptable rate of women missed for rapid testing 1% - Target rate 0%  \((\text{Sept} = 1.0\%)\)

Newborns with no refusal and not tested
- Target rate of newborns with no maternal refusal, not rapid tested 0  \((\text{Sept} = 5)\)

Documentation at discharge
- Minimum acceptable discharge documentation standard 95.5% - Target rate 100%  \((\text{Sept} = 99.98\%)\)
Undocumented Babies – Percentage of Total Deliveries

<table>
<thead>
<tr>
<th>Quarter</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
</tr>
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<tbody>
<tr>
<td>Q1</td>
<td>3.25%</td>
<td>1.70%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Q2</td>
<td>2.90%</td>
<td>1.65%</td>
<td>0.20%</td>
</tr>
<tr>
<td>Q3</td>
<td>3.05%</td>
<td>0.60%</td>
<td>0.04%</td>
</tr>
<tr>
<td>Q4</td>
<td>2.81%</td>
<td>0.02%</td>
<td>0.02%</td>
</tr>
<tr>
<td>Q1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q2</td>
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<td></td>
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<tr>
<td>Q3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q4</td>
<td></td>
<td></td>
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</tbody>
</table>
Documentation at Discharge

- Q4 2004: 92.0%
- Q1 2005: 94.8%
- Q2 2005: 95.1%
- Q3 2005: 97.1%
- Q4 2005: 97.9%
- Q1 2006: 98.4%
- Q2 2006: 98.3%
- Q3 2006: 99.4%
- Q4 2006: 99.9%
- Q1 2007: 99.9%
- Q2 2007: 99.9%
- Q3 2007: 99.9%
## Preliminary Positive Rapid Tests – 10/04 to 11/07

<table>
<thead>
<tr>
<th></th>
<th>Statewide (Illinois)</th>
<th>Cook-Chicago (only)</th>
<th>Cook - Suburban</th>
<th>Outside Cook</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Preliminary positives</td>
<td>98</td>
<td>55</td>
<td>17</td>
<td>24</td>
</tr>
<tr>
<td>True positives</td>
<td>71</td>
<td>43</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>False positives</td>
<td>27</td>
<td>12</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>False positive rate</td>
<td>27.6%</td>
<td>21.8%</td>
<td>29.4%</td>
<td>50.0%</td>
</tr>
</tbody>
</table>
True Positives Identified by Quarter, Oct 04 to present

- Jul-Sep 07
- Apr-Jun 07
- Jan-Mar 07
- Oct-Dec 06
- Jul-Sep 06
- Apr-Jun 06
- Jan-Mar 06
- Oct-Dec 05
- Jul-Sep 05
- Apr-Jun 05
- Jan-Mar 05
- Oct-Dec 04
Infant HIV Status, Oct 04 to present

- Mothers
- Negative infants
- Positive infants
- Fetal deaths
Holes in the Safety Net

- Illinois law still allows for religious refusal of mandatory newborn testing – originally developed for Amish population

- HIV testing of pregnant women in non-birthing hospitals is not universal

- Not all hospitals report preliminary positive rapid tests in a timely manner to allow real-time linkage with case management
Acknowledgments

The safety net of prevention would not be possible without the participation and support of the Illinois Department of Public Health, the PRTII regional coordinators, PACPI enhanced case managers, Illinois perinatal network administrators, Northwestern Memorial Hospital Hotline staff, Dr. Pat Garcia, Dr. Mardge Cohen, Sinai Urban Health Institute, AIDS Foundation of Chicago and all the nurse managers and staff on labor & delivery at the 133 birthing hospitals in Illinois.
Illinois Perinatal Legislation

- New law effective July 1, 2007:

- Current Illinois law, June 2006:
  [www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2483&ChapAct=410%26nbsp%3BILCS%26nbsp%3B335%2FChapterID=35&ChapterName=PUBLIC+HEALTH&ActName=Perinatal+HIV+Prevention+Act%2E](http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2483&ChapAct=410%26nbsp%3BILCS%26nbsp%3B335%2FChapterID=35&ChapterName=PUBLIC+HEALTH&ActName=Perinatal+HIV+Prevention+Act%2E)

- Original legislation, 2003:
Questions?

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