

Identification of Perinatal HIV Exposure for Public Health Action

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Ryan White Grantees' Meeting

The findings and conclusions in this presentation are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention



Introduction

- **Elimination of perinatal HIV infection is possible**
 - <1 infection/100,000 live births and <1% transmission rate
- **Effective interventions are well characterized**
 - Comprehensive healthcare for women (including routine HIV testing)
 - Universal, opt-out HIV testing for pregnant women
 - Family planning services for HIV-infected individuals
 - Antiretrovirals for HIV-infected (pregnant) women
 - Cesarean delivery when appropriate
 - Avoidance of breastfeeding
 - Antiretrovirals for exposed infants as post-exposure prophylaxis



Introduction (2)

- **74% of infected infants and 52% of uninfected exposed infants reported to CDC Enhanced Perinatal Surveillance system 2005-2008 had ≥ 1 missed prevention opportunity***
- **Estimated number of HIV-infected pregnant women increased ~30% between 2000 and 2006 to 8700**
- **Infections decreasing but still ~200 infants infected every year**
- **Many jurisdictions/states do not report perinatal HIV exposure to any central coordinator**

***Whitmore et al, unpublished EPS data, 2010**

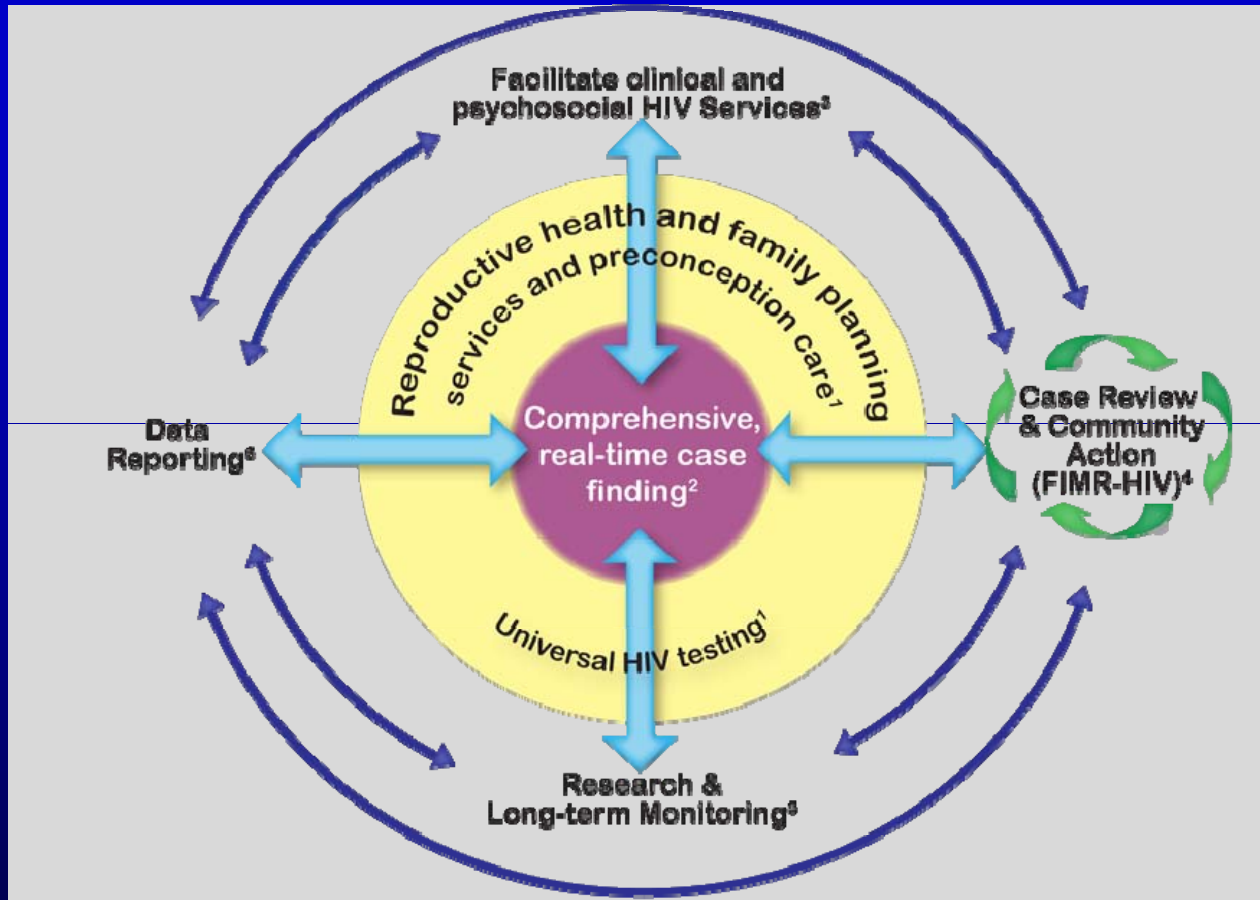


Introduction (3)

- Need to assure that HIV-infected women have the knowledge and tools to choose if and when to safely become pregnant
- Need to **identify** HIV-infected pregnant women and **assure** receipt of all appropriate services



Conceptual Framework for Elimination of Mother-to-Child Transmission of HIV (EMCT)



¹Reproductive health and family planning services, preconception care, and universal HIV testing are essential components of EMCT and facilitate ²comprehensive real-time case finding of all HIV-infected pregnant women. Real-time case finding enables: ³comprehensive clinical care and social services for women and infants; detailed review of select cases to identify and address missed prevention opportunities and local systems issues through continuous quality improvement⁴; research and long-term follow-up to develop and ensure safe, efficacious interventions for EMCT⁵; thorough data reporting for HIV surveillance and EMCT evaluation⁶.



Context

- **Some do most of this; others not as much**
- **Laws and policies differ in every jurisdiction**
- **This presentation outlines a conceptual framework for activities for a system to identify HIV-infected pregnant women**
- **Not an official policy or requirements of any agency or funding stream**
- **Clearly will be funding and possibly legal hurdles to full implementation of such a framework**
- **Ideas and discussion welcome**



Definitions

Identify all HIV-infected pregnant women in jurisdiction

- More than just “known HIV status”
- **Designated person for the entire jurisdiction** whose job it is to:
 - **Be informed about every HIV-infected pregnant woman** in the jurisdiction during the pregnancy (who can collect and de-duplicate data from all available sources)
 - Know enough about the care/services received by every woman to **identify missed prevention opportunities** (this implies active investigation of some sort)
 - Actively use this information to **assure receipt of appropriate services** by each woman
 - May be one person, part of a person, or more than one person, depending on needs of jurisdiction
 - May combine with other perinatal infections staff in some jurisdictions (e.g., hepatitis B has someone in every state who does this for perinatal hepatitis B)
- **Not (necessarily) surveillance**
 - This will often be **different from surveillance systems** as traditionally set up for HIV
 - Detecting fetal exposure, not necessarily infection
 - Reports used for immediate public health action (assuring each woman gets all needed services)
 - May report to surveillance (or even be surveillance staff), or may need to be completely separate, depending on local law/regulation



Definitions (2)

- **HIV-infected pregnant women**
 - Includes positive HIV tests in pregnant women
 - Universal HIV screening for pregnant women
 - Some method for reporting positives (lab-based, etc.)
 - **Pregnancy occurring in known HIV-infected women**
 - Getting all HIV-infected women into long-term care (not easy, of course)
 - Reproductive health/family planning services so all pregnancies are planned
 - Some method for reporting pregnancies to the perinatal HIV coordinator



Definitions (3)

- **Timeliness**
 - *During* pregnancy (not after baby is born)
 - Early enough in pregnancy to allow intervention (the earlier ART is started, the lower the chance of transmission)



Definitions (4)

- **Intervention/linkage**
 - assure that women get all services necessary to maximize their own health and minimize risk of transmission
 - Services may include case management, psychosocial, clinical, substance use, etc.
 - Assurance may include actual case-management functions or just monitoring/coordination/linkage



Significance

- **Mopping up missed prevention opportunities through linkage to care**
 - Women who transmit are those who fall through the cracks
 - Complex lives and diverse needs
- **Need to define population in need for your jurisdiction**
 - Data to argue for resources
 - Data to direct resources
 - Measure completeness of service provision



Models (1)

- **Direct contact with care providers**
 - Strong relationships with prenatal care providers, delivery hospitals for active case-finding
 - IRB? (depending on local laws, statues, and regulations)
 - **Population-based system (not facility based)**
 - Needs to be representative of total population of HIV-infected pregnant women/exposed infants (not just the biggest/easiest delivery hospitals or medical systems or cities)



Models (2)

- **Exposure reporting during pregnancy (by providers, labs)**
 - Report to coordinator, not (necessarily) reporting to surveillance system
 - Areas that have HIV exposure reporting laws have the authority (based on relevant State public health laws, statutes, rules, etc) to access HIV-infected mothers' and HIV-exposed infants' medical records
 - Need to ID exposed infants before delivery, though, which most systems don't currently do
 - Timeliness of identification/report



Models (3)

- **Lab-based reporting**
 - May be same as above
 - 2010 CSTE position statement
- **Perinatal hotline**
 - Set up and staff a phone number/website for reporting and assistance
 - One-stop service to providers
 - One-stop service to patients
 - Reporting mechanism



Models (4)

- **Detect pregnancy among HIV-infected women already in care**
 - Family planning services
 - Reporting by RW providers
 - Reporting by private providers
 - Active surveillance among providers
 - Lab-based systems

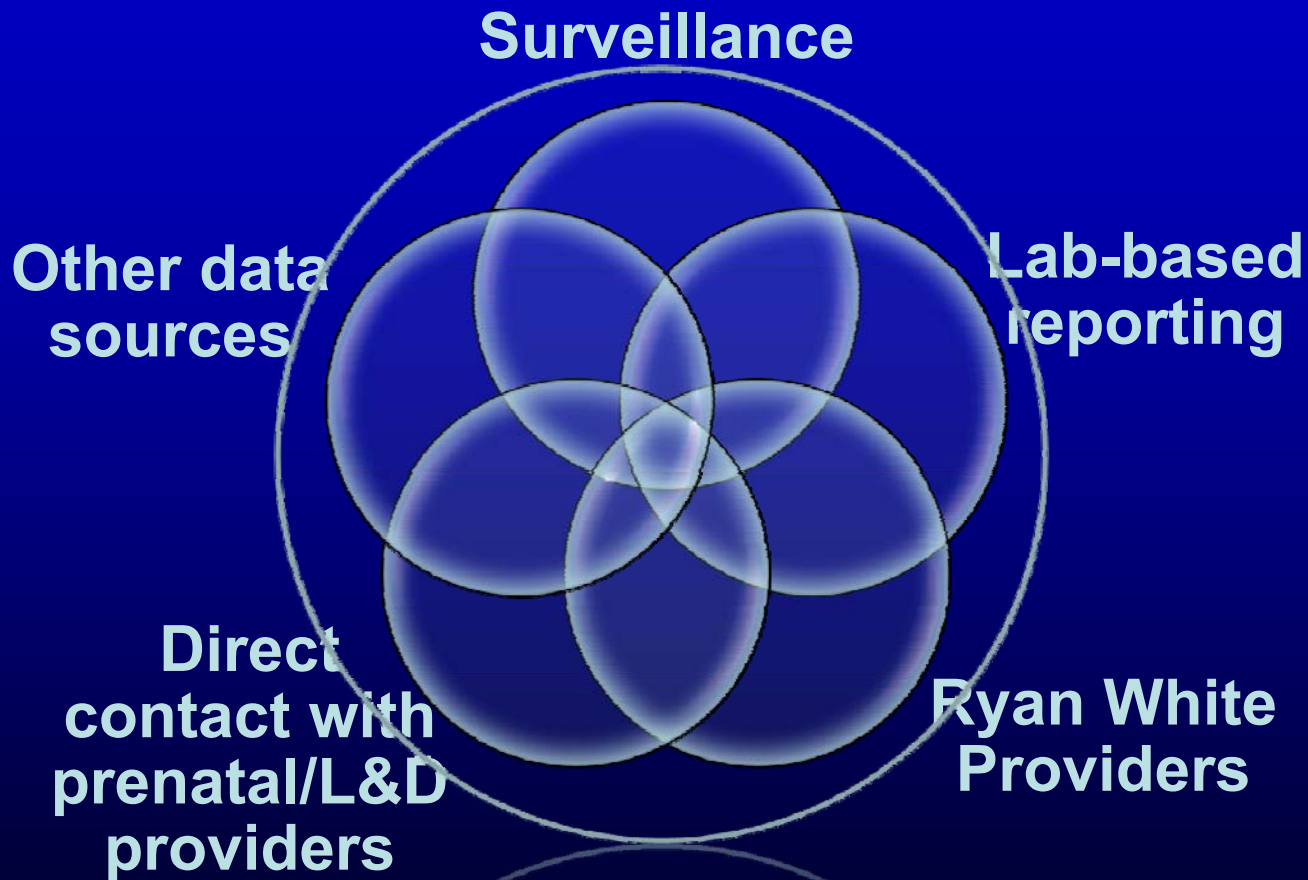


Models (5)

- **Birth registry vs. HIV surveillance matches as a late check to see who has been missed**
- **Follow up to 18 mo or until final status is determined (active, how to fund?)**
- **Many (most?) are doing at least some of this. Few are doing all of it. Fewer can estimate their completeness.**



Perinatal HIV Services Coordinator



Security and Confidentiality

- **Varies by state/local law/regulation**
 - Some jurisdictions have broad public health authority for activities directed at preventing spread of infectious diseases (e.g. DIS)
 - Other jurisdictions have special regulations/laws regarding HIV reporting/confidentiality



Ryan White Providers' Roles

- **Maximize women's health**
 - HIV care
 - One-stop shop (case management, psychosocial services, substance abuse services, etc. etc.)
- **Family Planning**
 - Prevent unintended pregnancy
 - Safe conception
- **Work with perinatal HIV coordinators**
 - Detect pregnancy and report to coordinator to assure linkage to other services
 - Direct linkage to affiliated services



What's in it for RW providers?

- **More complete care for clients**
- **Better define the needs of the population and advocate for more resources**
- **Better service coordination**



Conclusions

- **In order to eliminate remaining cases of perinatal HIV infection**
- **We need systems that can**
 - **Identify**
 - **in real time**
 - **all pregnant women with HIV infection**
 - **and all women with HIV infection who are pregnant**
 - **follow the care received by each woman over time**
 - **actively assure that necessary services are available and utilized**



Thank you

