ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT

IDPH

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PCM INTERSECT WITH THE MEDICAL WORLD ALONG WITH OTHER IMPORTANT PERINATAL CONSIDERATIONS

Helen E. Cejtin, MD, MPH
Obstetrician and Gynecologist
Stroger Hospital/Core Center
she/her

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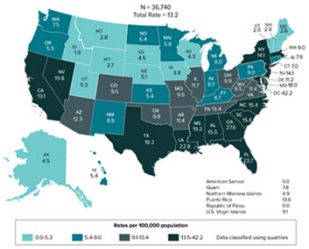
HIV INFECTION IN THE U.S. (CDC)

Figure 1. Rates of Diagnoses of HIV Infection among Adults and Adolescents, 2019—United States and 6 Dependent Areas



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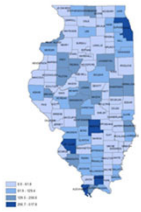
HIV IN ILLINOIS

Figure 15. Rate of Persons Living with HIV Disease by County, Illinois, 2013



DID YOU KNOW?

1 in **222** men in Illinois was living with diagnosed HIV disease in 2013

1 in **859** women in Illinois was living with diagnosed HIV disease in 2013

Note: County based on last known county of residence.
Source: Illinois Department of Public Health, June, 2014

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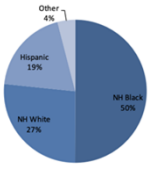
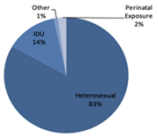
HIV IN ILLINOIS (cont.)

Figure 6. HIV Disease Diagnoses by Race/Ethnicity, Illinois, 2009–2013



Source: Illinois Department of Public Health, June, 2014

Figure 11. HIV Disease Diagnoses among Females by Transmission Risk Category, Illinois, 2009–2013



Note: 679 women with a transmission risk category not reported are excluded from the chart.
Source: Illinois Department of Public Health, June, 2014

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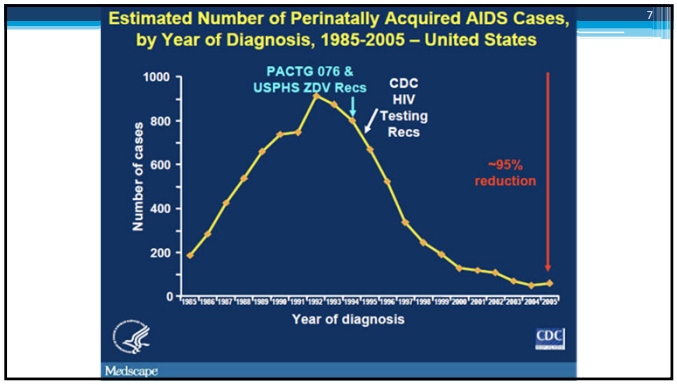
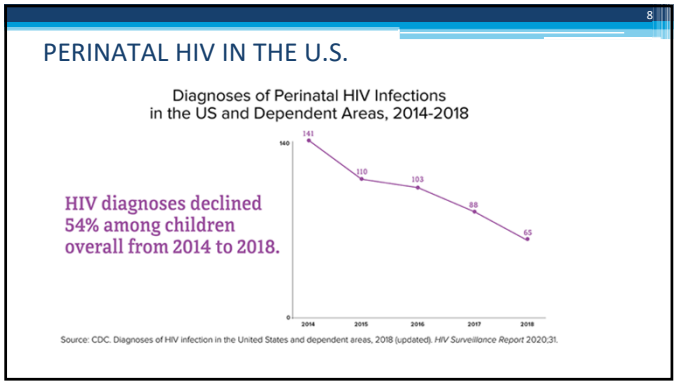

7
Estimated Number of Perinatally Acquired AIDS Cases, by Year of Diagnosis, 1985-2005 – United States
PACTG 076 & USPHS ZDV Recs
CDC HIV Testing Recs
~95% reduction
Number of cases
1000
800
600
400
200
0
1985 1986 1987 1988 1989 1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005
Year of diagnosis
Medscape

7


8
PERINATAL HIV IN THE U.S.
Diagnoses of Perinatal HIV Infections in the US and Dependent Areas, 2014-2018
HIV diagnoses declined 54% among children overall from 2014 to 2018.
140
141
110
103
88
65
2014
2015
2016
2017
2018
Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2018 (updated). HIV Surveillance Report 2020;31.

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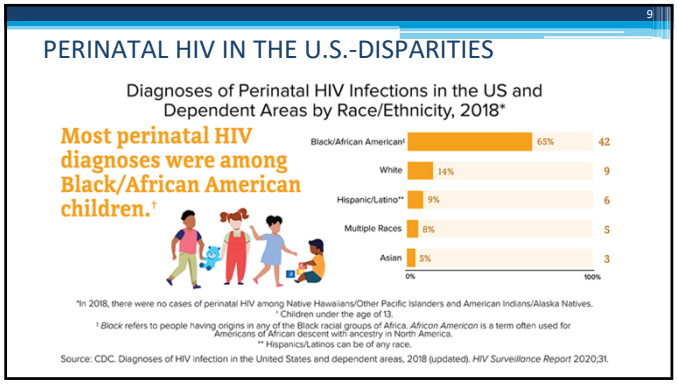
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PERINATAL HIV IN THE U.S.-DISPARITIES
Diagnoses of Perinatal HIV Infections in the US and Dependent Areas by Race/Ethnicity, 2018*
Most perinatal HIV diagnoses were among Black/African American children.†
Black/African American‡ 65% 42
White 14% 9
Hispanic/Latino** 9% 6
Multiple Races 8% 5
Asian 5% 3
0%
100%
*In 2018, there were no cases of perinatal HIV among Native Hawaiians/Other Pacific Islanders and American Indians/Alaska Natives.
† Children under the age of 13.
‡ Black refers to people having origins in any of the Black racial groups of Africa. African American is a term often used for Americans of African descent with ancestry in North America.
** Hispanics/Latinos can be of any race.
Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2018 (updated). HIV Surveillance Report 2020;31.

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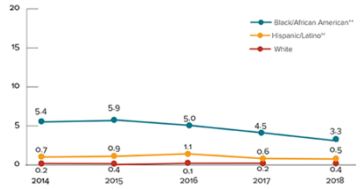
Rates of Perinatally-Acquired HIV Infections Among Persons Born in the United States, by Year of Birth and Mother's Race/Ethnicity, 2014-2018 *†‡



*Data include only persons born in the United States (50 states and District of Columbia). Data accounted for delays between birth and diagnosis, as well as between diagnosis and reporting.
†Rates are per 100,000 live births.
‡Live-birth data reflect race/ethnicity of the infant's mother.
**Black refers to people having origins in any of the Black racial groups of Africa. African American is a term often used for Americans of African descent with ancestry in North America.
††Hispanics/Latinos can be of any race.

Source: Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2018. *HIV Surveillance Supplemental Report* 2020;25(2).

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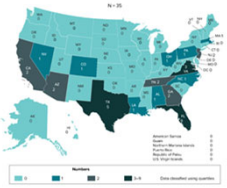
PERINATAL HIV IN U.S. AND ILLINOIS (CDC)

5000 PLWH GIVE BIRTH ANNUALLY IN U.S.

Figure 31. Diagnoses of Perinatally Acquired HIV Infection among Children Born During 2018—United States and 6 Dependent Areas



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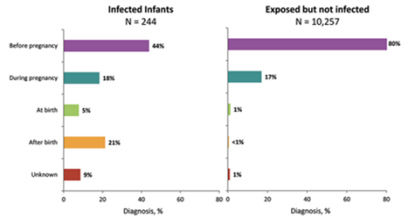
PERINATAL HIV INFECTION IN THE U.S.-TIMING OF Dx (CDC)

Figure 27. Time of Maternal HIV Testing among Children with Diagnosed Perinatally Acquired HIV Infection and Children Exposed to HIV, Birth Years 2014–2017—United States and Puerto Rico



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PERINATAL HIV PREVENTION BEGINS WITH HIV TESTING

TEST IN PREGNANCY IS UNIVERSAL, VOLUNTARY, OPT OUT (***NOT*** RISK-BASED)
TESTING SHOULD BE DONE:
AT FIRST PRENATAL VISIT
AFTER DIAGNOSIS OF OTHER STI
PERIODICALLY WITH ONGOING RISKY BEHAVIORS
IN THE 3RD TRIMESTER REGARDLESS OF RISK (ILLINOIS LAW)
RAPID TEST IN LABOR IF NO AVAILABLE 3RD TRIMESTER TEST RESULT

*hivinfo.nih.gov

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PERINATAL HIV PREVENTION ACT (410 ILCS 335)

PRENATAL TEST AS SOON AS POSSIBLE
3RD TRIMESTER TEST
TEST IN LABOR IF NO 3RD TRIMESTER TEST
TEST NEWBORN IF MOTHER REFUSES TESTING HERSELF
NEWBORN TEST=MATERNAL TEST (HIV ANTIBODY)
LAW IS ATTACHED TO CASE MANAGEMENT FOR MOTHER IF HIV POSITIVE

*

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CONSIDERATIONS FOR PREGNANT PEOPLE LIVING WITH HIV (PLWH)

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CONSIDERATIONS FOR PREGNANT PWH (cont.)

Comorbid conditions:
- Mental health
- Substance use
- Other STIs

Other issues:
- Discrimination
- Stigma
- Housing
- Custody
- Food insecurity

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CONSIDERATIONS IF NEWLY HIV-DIAGNOSED IN PREGNANCY

- May reconsider pregnancy options
- Questions about life expectancy
- Fear of transmission to baby
- Questions about acquisition
- Fear about health of other children
- Fear of infecting household contacts
- Fear of infecting partner(s)-PrEP
- Questions about route of delivery
- Trust issues

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CONSIDERATIONS IF NEWLY HIV-DIAGNOSED IN PREGNANCY (cont.)

- Fear of disclosure to partner:
  - Abandonment
  - Monetary loss
  - Housing instability
  - Intimate Partner Violence (IPV)
  - Disclosure to others

DO NOT RECOMMEND DISCLOSURE IN ALL CASES
DO NOT DISCLOSE TO PARTNER WITHOUT CONSENT
OFFER PARTNER NOTIFICATION SERVICES-15% ARE HIV+

www.cdc.gov/hiv/clinicians/screen/partner-notiifcation-services

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HIV DISCLOSURE LEGISLATION-ILLINOIS

JULY 29, 2021-SENATE BILL 655
2nd STATE IN U.S. TO FULLY DECRIMINALIZE HIV TRANSMISSION
PREVIOUSLY A CLASS 2 FELONY TO HAVE SEX/NOT DISCLOSE
ASSOCIATED WITH <=7 yr/$25,000 FINE
- STIGMATIZATION
- NOT SCIENTIFICALLY SUPPORTED

https://www.them.us/story/illinois-fully-decriminalizes-hiv-transmission#

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HIV TESTING/DISCLOSURE LEGISLATION-ILLINOIS

PEOPLE AGED >=12y CAN GET HIV TEST WITHOUT PARENTAL PERMISSION

IF A MINOR TESTS POSITIVE, PROVIDER ***CAN*** TELL PARENTS IF BENEFICIAL

PROVIDER CANNOT TELL FRIENDS/FAMILY/EMPLOYER ABOUT HIV STATUS

PROVIDER CAN ONLY TELL ***LEGAL SPOUSE*** ABOUT HIV STATUS IF THEY HAVE ENCOURAGED PATIENT TO TELL (USUALLY NOT ADVISED)

PROVIDER IS ***NEVER*** MANDATED TO DISCLOSE HIV SEROSTATUS TO PARENTS/PARTNERS

www.aidschicago.org

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22
COMPLERA
Genvoya
Dovato
dolutegravir 50 mg/
lamivudine 300 mg tablets

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23
Enter Your Search Term...
In affiliation with HIV.gov
Guidelines
Drug Database
Glossary
News
Mobile Applications
Resources
Contact Us
Language (EN)
HOME > GUIDELINES > What's New in the Guidelines
Recommendations for the Use of Antiretroviral Drugs in Pregnant Women with HIV Infection and Interventions to Reduce Perinatal HIV Transmission in the United States
The information in the brief version is excerpted directly from the full-text guidelines. The brief version is a compilation of the tables and boxed recommendations.
https://clinicalinfo.hiv.gov/en/guidelines/perinatal/whats-new-guidelines Updated February 10, 2021

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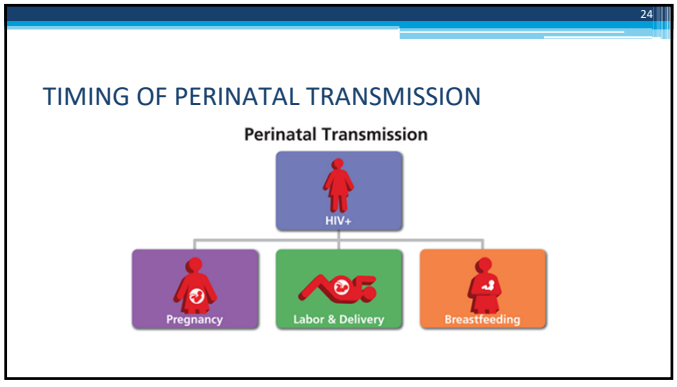
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TIMING OF PERINATAL TRANSMISSION
Perinatal Transmission
HIV+
Pregnancy
Labor & Delivery
Breastfeeding

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PREVENTION OF PERINATAL HIV TRANSMISSION

3-PRONGED:

ART DURING THE PREGNANCY

IV AZT DURING LABOR

NEONATAL ART

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RISK OF PERINATAL HIV TRANSMISSION

OFF MEDICATION:

ON MEDICATION:

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ANTEPARTUM CARE

- Prenatal care should come from a provider/center with experience treating PWH in pregnancy
- Expect increased prenatal visits
- Expect increased blood work

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CONSIDERATIONS FOR ANTEPARTUM ANTIRETROVIRAL THERAPY (ART)

- Treatment necessary regardless of maternal HIV RNA
- Risk of transmission to newborn is 24% without treatment
- Risk of transmission to newborn is 1% in best case
- ART should be started ***as soon as possible***
- During pregnancy people may be asked to change their ART

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INTRAPARTUM CONSIDERATIONS FOR PWH

- Delivery should be at a hospital with experience treating PWH in pregnancy
- Patient should go to hospital early
- Cesarean section only recommended if HIV viral load>1000 at end of pregnancy
- Patient will likely receive IV AZT while in labor
- Warn hospital staff if support person does not know serostatus

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POSTPARTUM CONSIDERATIONS FOR PLWH

- BREASTFEEDING IS CONTRAINDICATED, ***EVEN IF UNDETECTABLE***
- ANALGESICS/ICE/BINDERS FOR BREAST ENGORGEMENT
- POSTPARTUM DEPRESSION IS COMMON
- SOME ART INTERACT WITH CONTRACEPTION

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CONSIDERATIONS FOR NEWBORN CARE

All HIV-exposed babies need ART ASAP after delivery, preferably within 6 hours:

- ***Low-risk*** babies-zidovudine (AZT) 2x daily for 4 wks
- ***High-risk*** babies-3 drugs 2x daily for 4-6 wks

HIV-PCR testing for newborns (can't use HIV Ab test):

- 2-3 weeks
- 1-2 months
- 4-6 months
- Additional test at birth and 2-6 wks after ART in ***High-risk*** babies

Baby's blood counts are monitored

Presumptive negative at second test (>=1m and >=4m)

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GETTING TO ZERO ILLINOIS

Getting to Zero Illinois is a state-wide initiative to end the HIV epidemic in the state by 2030. Through partnerships with people living with HIV, community-based organizations, health care providers, government agencies and others, we can dramatically shift HIV in Illinois. AIDS Foundation Chicago and the Illinois and Chicago Departments of Public Health coordinate the Getting to Zero Illinois project.

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QUESTIONS?

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ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT

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PRE-EXPOSURE PROPHYLAXIS (PrEP)

Medications used to prevent HIV
- Approved for those at risk for HIV, including discordant couples or IDU
- Once daily pill (two medications in one pill)
- Must be HIV-negative and have good kidney function
- Must agree to HIV, other STI, and kidney function tests every 3 months
- Safe in pregnancy
- Cost $$

Concerns
- Current medication (Truvada) can rarely affect kidneys
- Alternative medication (Descovy) only for individuals born male
- Stigma of taking HIV-related medication
- Must take consistently to be most effective
  - Up to 99% effective against sexual transmission if taken daily
- PrEP only protects against HIV, so condoms should be used to prevent other STI's
- 21 days PrEP before safe IDU or vaginal sex/7 days PrEP before safe for males
- U=U: Undetectable=Untransmittable

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CASE MANAGEMENT TIERS

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CASE MANAGEMENT TIERS

1. **Non-Medical Case Management**
   - Retention Specialist
   - Medical Benefit Coordinator
   - Peer Navigator
   - Client Representative (only non-paid staff and federally mandated)
2. **Medical Case Management**
   - Ryan White Medical Case Management (MCM) – traditional medical case management
   - Corrections Case Management (CCM) – includes all duties of MCM but with additional requirements to assist the recently-released population
   - Perinatal Case Management (PCM) – includes all duties of MCM but with additional requirements relating to prevention of transmission

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CASE MANAGEMENT TIERS

Non-Medical Case Management

HRSA Definition: provision of a range of program **participant-centered** activities focused on improving access to and retention in core medical and support services. NMCM provides coordination, guidance, and assistance in accessing medical, social, community, legal, financial, employment, vocational, and/or other needed services. Services may also include assisting eligible program participants to obtain access to other public and private programs for which they may be eligible, such as Medicaid, Medicare Part D, Medication Assistance Programs, Pharmaceutical Manufacturer's Patient Assistance Programs, Department of Labor or Education-funded services, other state or local health care and supportive services, or private health care coverage plans.

Key activities include:

- Initial assessment of needs.
- Ongoing assessment of the program participant's and other key family members' needs and personal support systems.
- Timely and coordinated access to medically appropriate levels of health and support services and continuity of care.
- Program participant-specific advocacy and/or review of utilization of services.

✔ **This service category includes several methods of communication, including face-to-face meetings, phone contact, and any other forms of communication deemed appropriate by the Program (e.g.: texting, email correspondence).**

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MEDICAL CASE MANAGEMENT

Medical Case Management

HRSA Definition: the provision of a range of program participant-centered activities focused on improving health outcomes in support of the HIV care continuum. Activities provided under this service category may be provided by an interdisciplinary team that includes other specialty care providers.

Key activities include:

- All activities outlined in Non-Medical Case Management, **plus…**
- Initial assessment of needs.
- Development of a comprehensive, individualized care plan.
- Timely and coordinated access to medically appropriate levels of health and support services and continuity of care.
- Continuous program participant monitoring to assess the efficacy of the care plan.
- Re-evaluation of the plan every 6 months unless updated.
- Ongoing assessment of the program participant's and other key family members' needs and personal support systems.
- Treatment adherence counseling to ensure readiness for and adherence to complex HIV treatments.
- Program participant-specific advocacy and/or review of utilization of services.

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PERINATAL CASE MANAGEMENT

Perinatal Case Management

Definition: Perinatal Case Management (PCM) is an intensive form of Medical Case Management that concentrates on medical factors and specific concerns relating to pregnancy and transmission.

Objective: Reduce the risk of mother to child HIV transmission by supporting linkage to care and medication adherence for HIV positive pregnant women and their infants.

Key Activities:

- All duties required for Medical Case Management, **plus…**
- Understanding perinatal transmission of HIV.
- Comprehension of testing requirements for pregnant women and newborns and related follow up.
- Understanding medication and side effects for mother and baby.
- Assessment of mother and baby at multiple stages after delivery.

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KEY ELEMENTS OF PERINATAL HIV RESOURCE NETWORK

- Illinois HIV Perinatal Prevention Act
- Illinois 24/7 Perinatal HIV Hotline
- Illinois RWPB Perinatal Case Management
- Pediatric HIV Exposure Reporting Surveillance (PHERS)
- Fetal and Infant Mortality Review-HIV/Congenital Syphilis (FIMR-HIV/CS)

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THE PERINATAL RESOURCE NETWORK OF ILLINOIS

Key elements of the safety net include:

- 24/7 Illinois Perinatal HIV Hotline (**1-800-439-4079**).
- Rapid HIV testing in labor and delivery units and maternal hospitals throughout the state.
- Perinatal Case Management for mothers with HIV and their infants.
  - ✔ Currently, approximately 2-4 confirmed mother-to-child HIV infections per year occur in the state of Illinois.
  - ✔ The goal is eventual elimination of perinatal HIV transmission.

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Slide 41

1 Can these all be under umbrella of Perinatal Safety Net? It seems like the Act establishes the hotline, requires testing, and mandates case management of those with + results.
Koechle, Jennifer, 12/11/2020

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PERINATAL HIV PREVENTION ACT

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PERINATAL HIV PREVENTION ACT (410 ILCS 335)

- This law mandates HIV counseling and testing for pregnant mothers whose HIV status is unknown in the 3rd trimester.
- At birth, if mother has unknown status and refuses testing, the parent or guardian is counseled, and the infant is given a rapid HIV test by the health care provider.
- 24/7 Illinois Perinatal HIV Hotline was established to educate health care providers in order to prevent transmission of HIV during labor and delivery.
- Health care providers must report preliminary positive test results to the Illinois Perinatal HIV Hotline within 12 hours, but not later than 24 hours, of receiving the test result.
- The Department or its authorized representative shall provide case management services to the preliminarily positive pregnant or post-partum woman or the parent or guardian of the preliminarily positive newborn infant to ensure access to treatment and care and other services where the pregnant or post-partum woman or the parent or guardian of the newborn infant has consented to the services.

http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2483&ChapterID=35

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MANDATORY PERINATAL HIV COUNSELING

Counseling of the pregnant woman must be provided in accordance with the AIDS Confidentiality Act and must include the following:

- Voluntary nature of testing, benefits of HIV testing, requirement that HIV testing be performed unless she refuses, and methods of refusal,
- Benefits of HIV testing for herself and newborn (including prevention of transmission),
- Interventions to prevent HIV transmission and their side effects,
- Statutory confidentiality provisions that relate to HIV testing,
- Requirement for mandatory testing of the newborn if the mother's HIV status is unknown at the time of delivery,
- Explanation of the test, including its purpose, limitations, and the meaning of its results,
- Explanation of the procedures to be followed, and
- Availability of additional or confirmatory testing, if appropriate.

Counseling may be provided in writing, verbally, by video, electronically, or by other means. The pregnant woman must be offered an opportunity to ask questions about testing and to decline testing for herself.

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MANDATORY PERINATAL HIV TESTING

Mandated testing offers an opportunity for early HIV screening for pregnant women and must include:

- ❑Mandatory *offering* of HIV testing to all pregnant women (testing must be *voluntary*)
- ❑Repeat testing in the early 3rd trimester for all pregnant people
- ❑Rapid tests *offered* during labor and delivery to women without a documented 3rd trimester HIV test
- ❑**Mandatory newborn testing** when the mother's status is unknown at birth, and
- ❑All preliminary positive rapid HIV results of mothers and infants reported to the 24/7 Illinois Perinatal HIV Hotline (**1-800-439-4079**) within 24 hours of birth to ensure medical consultation and linkage to case management.

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24/7 ILLINOIS PERINATAL HIV HOTLINE

- Statewide resource for medical and social service providers caring for pregnant mothers with HIV
- Staffed by trained health care providers
- Up-to-date treatment recommendations regarding HIV during pregnancy and infants exposed to HIV
- Official reporting mechanism for preliminary positive rapid HIV results performed on mothers and infants
- Referral source that initiates follow-up and case management services
- Support for hospital staff relating to rapid test reporting

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PERINATAL CASE MANAGEMENT

Related Laws/Disclosure

- Illinois AIDS Confidentiality Act
  - https://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=1550
- Illinois HIV Criminal Transmission Law
  - http://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=072000050HArt%2E+12&ActID=1876&ChapterID=53&SeqStart=21000000&SeqEnd=30700000
- Ryan White Comprehensive AIDS Resources Emergency (CARE) Act
  - legislationtitlexxvi.pdf (hrsa.gov)
- Illinois Perinatal HIV Prevention Act
  - http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2483&ChapterID=35
- HIPAA Rules
  - https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/administrative/combined/hipaa-simplification-201303.pdf

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ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT TRAINING

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PERINATAL CASE MANAGEMENT OVERVIEW

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PERINATAL CASE MANAGEMENT

Perinatal Case Management goals include:

- Linking high-risk pregnant mothers who are HIV positive to the health care system
- Providing core and support services, including medication adherence counseling, to help prevent HIV transmission to the infant
- Supporting pregnant women with HIV who need extra assistance during and up to 18 months after their pregnancies end to maintain viral suppression and self-sufficiency
- Coordinating services to ensure:
  - Women get the help and support needed to ensure a healthy pregnancy and birth
  - Postpartum care for both mother and her HIV-exposed infant
- Assisting women across the state to utilize the RWPB regional lead agent network

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PERINATAL CASE MANAGEMENT

Perinatal Case Management requires:

- A rigorous series of encounters with a program participant to discuss needs, barriers, and solutions to issues that are related to program participant's pregnancy
- Intensive communication between a program participant and Case Manager to ensure an overall standard of care concept is implemented that addresses health outcomes for both mother and baby
- Services to PCM program participants very similar to MCM program participants, plus additional education relating to perinatal transmission
- A level and frequency of contacts that will vary depending on program participant, stage of pregnancy, and identified needs, which includes mandatory home visits
- Pregnancy assessments that are completed at specific timeframes

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PERINATAL CASE MANAGEMENT

Required Education and Training

- Perinatal Case Managers are encouraged to have training in a medical-related field that provides them with a comprehensive understanding of medical terminology, maternal/child health, and substance abuse care and treatment.
- Perinatal Case Managers must be familiar with HHS Clinical Guidelines and HRSA Clinical Protocols that explain current information about HIV treatment, transmission, prevention, and medications.
  - Clinicalinfo | Information on HIV/AIDS Treatment, Prevention and Research
  - Maternal HIV Testing and Identification of Perinatal HIV Exposure | Pediatric ARV | ClinicalInfo
  - Diagnosis of HIV Infection in Infants and Children | Management of Infants Born to Women with HIV Infection | Perinatal | ClinicalInfo
  - Introduction | Pediatric ARV | ClinicalInfo (hiv.gov)
  - Pregnant & Positive | Perinatal HIV Hotline (hivpregnancyhotline.org)

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PERINATAL CASE MANAGEMENT

Clinicalinfo | Information on HIV/AIDS Treatment, Prevention and Research

Offering Information on HIV/AIDS Treatment, Prevention, and Research

- Clinical Guidelines: Federally approved medical practice guidelines for HIV/AIDS
- Drug Database: Information on FDA-approved HIV/AIDS and opportunistic infection drugs and investigational HIV/AIDS drugs
- Glossary: Medical dictionary of HIV-related terms
- Resources: HIV-related resources from the National Institutes of Health

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PERINATAL CASE MANAGEMENT

Maternal HIV Testing and Identification of Perinatal HIV Exposure | Pediatric ARV | ClinicalInfo

- Maternal HIV Testing and Identification of Perinatal HIV Exposure

Diagnosis of HIV Infection in Infants and Children | Pediatric ARV | ClinicalInfo

- Diagnosis of HIV Infection in Infants and Children
  - Timing of Diagnostic Testing in Infants with Perinatal HIV Exposure
  - Diagnostic Testing in Children with Perinatal HIV Exposure in Special Situations
  - Diagnostic Testing in Children with Non-perinatal HIV Exposure or Children with Perinatal HIV Exposure Aged >24 Months

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PERINATAL CASE MANAGEMENT

Introduction | Pediatric ARV | ClinicalInfo (hiv.gov)

Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection

- Clinical and Laboratory Monitoring of Pediatric HIV Infection
- When to Initiate Therapy in Antiretroviral-Naive Children
- Regimens Recommended for Initial Therapy of Antiretroviral-Naive Children
- Regimens Not Recommended for Initial Therapy of Antiretroviral-Naive Children
- Antiretroviral Management of Newborns with Perinatal HIV Exposure or HIV Infection
- Adherence to Antiretroviral Therapy in Children and Adolescents Living with HIV

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PERINATAL CASE MANAGEMENT

Perinatal HIV Hotline (hivpregnancyhotline.org)

- **1-800-439-4079**
- Reporting of Rapid Perinatal HIV Testing Results
- Sharing Medical Information and Guidelines with Providers
- Linkage to Care (Ryan White case management and/or medical care)
- Education on IL Law and Reporting
- Collects Patient Information for Service Provision/Referral Integrity
- Resources for Medical Providers and Case Managers
- Research and News

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PERINATAL CASE MANAGEMENT

- Perinatal Case Management often involves intensive coordination between multiple parties, including the 24/7 Illinois Perinatal HIV Hotline and medical providers, to ensure that an overall continuity of care concept is implemented for both mother and baby.
- Program participant referrals are received from a variety of sources, including hospitals, public and private agencies, the 24/7 Illinois Perinatal HIV Hotline, and self-referrals.
- The Case Manager should work with the Perinatal program participant's medical providers to immediately assess needs and urgency of response.
  - The PCM must contact perinatal program participants within two (2) business days of referral for non-emergent cases to schedule an intake appointment.
  - **If program participant needs immediate assistance or an urgent response, the PCM must respond immediately to the mother/infant needs.**

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PERINATAL CASE MANAGEMENT

Perinatal Case Management program participants must:

- Meet the overall eligibility requirements for the Ryan White Part B Program, **and**
- Not be currently receiving any other RWPB Case Management services, **and**
  - Currently be pregnant, **or**
  - Have been pregnant within the last 12 months (but does not require that pregnancy end with live birth).

✔ **Clients cannot be enrolled in more than one form of Case Management at a time.**

✔ **Perinatal Case Management program participants may be transitioned to another form of case management when all issues and needs related to their pregnancy/post-partum period are resolved, which could extend up to 18 months after end of pregnancy.**

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ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT TRAINING

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RYAN WHITE PART B
PERINATAL CASE MANAGEMENT
(PCM)

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PERINATAL CASE MANAGEMENT

- The RWPB Acuity Scale should be completed with pregnancy questions appropriately marked, which indicates the client should be enrolled into Perinatal Case Management.
- Case managers should utilize the Provide Enterprise system to enroll the client into PCM.
- The RWPB Eligibility Assessment (EA) is required before any services are provided.
  - IDPH gives priority to pregnant women when reviewing Eligibility Assessments.
  - The "Pregnancy" question should be answered affirmatively, and details of the pregnancy should be added before submitting EA, which will launch the Pregnancy Record in Provide.

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PERINATAL CASE MANAGEMENT

- A comprehensive intake process with HIV positive pregnant women referred for services should be completed within the first 30 days of enrollment, unless an urgent response is mandated.
- Client intake should be completed in conjunction with the Care Plan.
- Additional assessments at specific milestones must also be completed using the Life Cycle Tool.
- The frequency of contacts will vary depending on the stage of pregnancy and/or program participant or baby needs but may range between daily, weekly, or monthly interactions upon initial enrollment.
  - Home visits must be completed as dictated by policy and pregnancy stage.

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PERINATAL CASE MANAGEMENT

Required Assessments

- Depending on the pregnancy stage (prenatal or postnatal), the timing of the assessments may vary, but each assessment should be completed for each perinatal program participant, as applicable.
- The revised Life Cycle Tool includes the following assessments:
  - **Entry/Prenatal Phase** (within 7 days of entry)
  - **Labor, Delivery, and Birth Phase** (after birth)
  - **Post-Partum Phase** (after post-partum medical visit or within 8 weeks after birth)
  - **Family Planning Phase** (flexible as per the case manager's desecration or upon discharge/transfer from PCM on or at the 18-month period)
- The Ryan White Part B Program has significantly revised the PCM Assessments were utilized in the past in PE. The following slide will outline the new Life Cycle Tool and data entry requirements that will be utilized moving forward.

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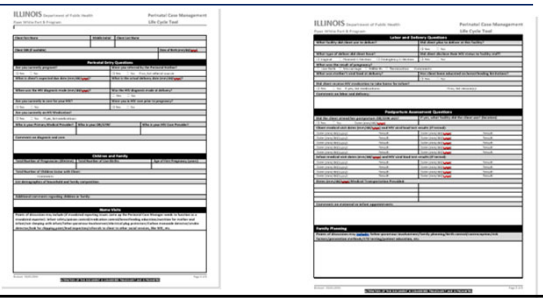
LIFE CYCLE TOOL (see Attachment)



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LIFE CYCLE TOOL - Entry Questions

ILLINOIS Department of Public Health
Ryan White Part B Program

Perinatal Case Management
Life Cycle Tool

Client First Name	Middle Initial	Client Last Name

Client SSN (if available)	Date of Birth (mm/dd/yyyy)

Perinatal Entry Questions

Are you currently pregnant?	Were you referred by the Perinatal Hotline?
☐ Yes ☐ No	☐ Yes ☐ No If no, list referral source:
What is client's expected due date (mm/dd/yyyy)?	What is the actual delivery date (mm/dd/yyyy)?
When was the HIV diagnosis made (mm/dd/yyyy)?	Was the HIV diagnosis made at delivery?
	☐ Yes ☐ No
Are you currently in care for your HIV?	Were you in HIV care prior to pregnancy?
☐ Yes ☐ No	☐ Yes ☐ No
Are you currently on HIV Medication?	
☐ Yes ☐ No If yes, list medications:	

Who is your Primary Medical Provider?	Who is your OB/GYN?	Who is your HIV Care Provider?

Comments on diagnosis and care:

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LIFE CYCLE TOOL - Household Composition/Home Visit

Children and Family		
Total Number of Pregnancies (lifetime):	Total Number of Live Births:	Age of First Pregnancy (years):
Total Number of Children Living with Client:		
Comments:		
List demographics of household and family composition:		
Additional comments regarding children or family:		

Home Visits
Points of discussion may include (if mandated reporting issues come up the Perinatal Case Manager needs to function as a mandated reporter): Infant safety/poison control/medication control/breastfeeding education/nutrition for mother and infant/not sleeping with infant/father-paramour involvement/electrical plug protectors/Carbon monoxide detector/smoke detector/look for chipping paint/lead inspection/referrals to client to other social services, like WIC, etc.

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LIFE CYCLE TOOL - Labor and Delivery Questions

Labor and Delivery Questions	
What facility did client use to deliver?	Did client plan to deliver at this facility?
	☐ Yes ☐ No
What type of deliver did client have?	Did client disclose their HIV status to facility staff?
☐ Vaginal ☐ Planned C-Section ☐ Emergency C-Section	☐ Yes ☐ No
What was the result of pregnancy?	
☐ Live Birth ☐ Miscarriage ☐ Stillbirth ☐ Termination Comments:	
What was mother's viral load at delivery?	Has client been educated on breastfeeding limitations?
	☐ Yes ☐ No
Did client receive HIV medication to take home for infant?	
☐ Yes ☐ No If yes, list medications:	If no, list reason(s):
Comments on labor and delivery:	

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LIFE CYCLE TOOL - Postpartum Questions

Postpartum Assessment Questions			
Did the client attend her postpartum OB/GYN visit?		If yes, what facility did the client use? (location)	
☐ Yes ☐ No Date (mm/dd/yyyy):			
Client medical visit dates (mm/dd/yyyy) and HIV viral load test results (if tested):			
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Infant medical visit dates (mm/dd/yyyy) and HIV viral load test results (if tested):			
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Date (mm/dd/yyyy):	Result:	Date (mm/dd/yyyy):	Result:
Dates (mm/dd/yyyy) Medical Transportation Provided:			
Comments on maternal or infant appointments:			

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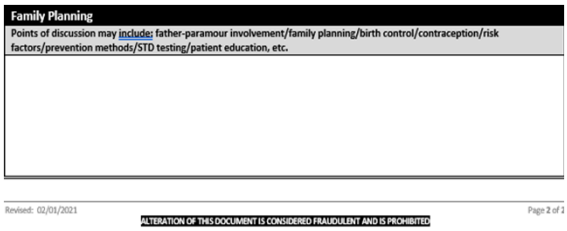
LIFE CYCLE TOOL - Family Planning Questions



Family Planning
Points of discussion may include: father-paramour involvement/family planning/birth control/contraception/risk factors/prevention methods/STD testing/patient education, etc.

Revised: 02/01/2021 Page 2 of 1

ALTERATION OF THIS DOCUMENT IS CONSIDERED FRAUDULENT AND IS PROHIBITED

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RYAN WHITE PART B
SERVICE PROVISIONS FOR PCM

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ALLOWABLE SERVICE CATEGORIES

Core Services

Medical Case Management
Outpatient Health Services
Medical Nutrition Therapy
Oral Health Care
Mental Health
Substance Abuse Treatment

NOTE: This is not the entire list of allowable core service categories.

For a complete list, please refer to HRSA Policy Clarification Notice 16-02 as well as the Program Manual.

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ALLOWABLE SERVICE CATEGORIES

Support Services

Medical Transportation
Housing Services
Treatment Adherence
Legal Services
Food Bank
Emergency Financial Assistance
Linguistic Services

NOTE: This is not the entire list of allowable support service categories. For a complete list, please refer to HRSA Policy Clarification Notice 16-02 as well as the Program Manual.

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CLARIFICATION OF TRANSPORTATION SERVICES

- **Medical Transportation** – transport of an eligible individual to access HIV-related medical services through either direct transportation services, vouchers, or tokens
  - Outpatient Ambulatory Health Care – primary care, HIV specialists, pediatrician
  - Oral Health Care
  - Mental Health Services
  - Substance Abuse Treatment
- **Supportive Transportation (included under Emergency Financial Assistance)** – transport of an eligible individual to access supportive services through either direct transportation services, vouchers, or tokens
  - Services relating to eligibility – case manager visits, Social Security office, DMV, insurance office
  - Ancillary services – food pantry, housing referrals, other social service referrals

****Reminder – RWPB Case Managers are not allowed to transport clients.****

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PERINATAL CASE MANAGEMENT

Referrals

- RWPB Perinatal Case Management clients have a complex combination of needs and may require specialized referrals.
- Not only will they likely need referrals to common HIV-related services, but they may also require specialized referrals relating to their pregnancies.
  - Medical care for themselves and their babies
  - Medication counseling to prevent side effects to the clients and their babies
  - Intensive substance abuse or mental health treatment, if appropriate

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CONSIDERATIONS FOR NEWBORN CARE

- In the US, breastfeeding is not recommended.
- All newborns exposed to HIV will need to take antiretroviral therapy for 4-6 weeks after birth
- Pre-mastication (chewing food for baby) should not be done.
- Regular pediatric follow-up with medical provider should be scheduled and coordinated with mother's appointments, if possible.
- Additional services, such as WIC, family case management, public health nursing home visits, should be sought.
- Insurance, including infant coverage and medications, should be reviewed.
- Housing and childcare referrals should be made, if needed.
- Availability of transportation should be confirmed.
- A transition plan (who continues to follow Mom and newborn) should be developed, if needed.

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IMPORTANCE OF CARE COORDINATION

Besides coordinating actual medical care appointments with health care providers, Perinatal Case Managers can assist clients with:

- Educating providers about working with clients with HIV
- Reducing stigma and judgment
- Ensuring that clients discuss important topics with medical providers
  - Options for family planning with clients who have HIV
  - Gender-specific HIV treatment options
  - Medication concerns during pregnancy (side effects for mother and baby)
  - Consequences of unprotected sex with male partners who may have HIV

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IMPORTANCE OF CARE COORDINATION

- Monitor viral load and medication adherence
- Maintain retention in care
- Implement screening of pregnant women and babies
- Work with program participants to minimize HIV risk to infants
- Discuss importance of family counseling and planning for women and men who are HIV positive
- Understand the utility of PrEP (Pre-Exposure Prophylaxis)

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PERINATAL CASE MANAGEMENT CONSIDERATIONS

- Sexual Practices
  - Sexual orientation
  - Sexual history
  - Number of current partners
  - Negotiating safer sex/PrEP
  - STD's
- Health/Illness
  - Medication Adherence
  - Disability
  - Death
- Family Planning
  - Pregnancy
  - Birth process
  - Breastfeeding
  - Child Care
  - Role of partner
- Substance abuse
  - Recovery/Medically assisted treatment (MAT)
- Mental Illness
  - Treatment
- Homelessness
  - Poverty
  - Unemployment
  - Underemployment
- Insurance
  - Public Benefits
- Domestic Violence
  - Child Abuse
  - Incest
  - Rape
- Corrections-involved
- Sex Worker

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ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT TRAINING

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PEDIATRIC HIV EXPOSURE REPORTING SURVEILLANCE (PHERS)
and
FETAL AND INFANT MORTALITY REVIEW (FIMR-HIV/CS)

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PEDIATRIC HIV EXPOSURE REPORTING SURVEILLANCE (PHERS)

- Number of infected women who present with known HIV status
- Number of pregnant women rapidly tested for HIV in L&D
- Number of newborn infants rapidly tested for HIV
- Number of preliminarily positive pregnant women
- Preliminarily HIV-exposed newborn infants identified
- Other information determined necessary

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FETAL AND INFANT MORTALITY REVIEW (FIMR-HIV/CS)

- Implemented in 2009 for HIV
- Added Congenital Syphilis in 2014
- PHER Surveillance data used to identify cases
- EMR Abstraction/Maternal Interview
- Multidisciplinary team reviews
- Community Action Team makes changes
- Ryan White Part B Grant Agreement Language: All Regions are required to "work in collaboration with and comply with Fetal & Infant Mortality Review (FIMR) requests."

Case Identification → Data Abstraction → Maternal Interview → Case Review Team → Community Action Team

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ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT

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PERINATAL CASE MANAGEMENT

To summarize, key activities include:

- All duties required for Medical Case Management, **plus…**
- Understanding of perinatal transmission of HIV.
- Assistance with developing a Birth Plan, if requested by client.
- Comprehension of testing requirements for pregnant women and newborns and related follow up.
- Counseling clients on breastfeeding and other behaviors to minimize transmission.
- Understanding medication and side effects for mother and baby.
- Completion of multiple assessments of mother and baby at specific timeframes.
- Provide adherence support for medical appointments (coordination, documentation, follow-up, providing transportation assistance, etc.) for both the mother and infant.
- Perform hospital and home visits as needed.

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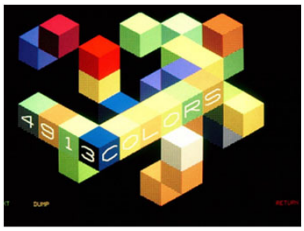
PROVIDE ENTERPRISE CHANGES

Provide Enterprise Demonstration
Discuss of Pregnancy Record and Progress Logs



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ILLINOIS RYAN WHITE PART B PROGRAM
PERINATAL CASE MANAGEMENT

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This concludes the Illinois Ryan White Part B Perinatal Case Management Training.

Thank you for your attention today. Please let the Program know if you have further comments or questions.

IDPH
Illinois Department of Public Health

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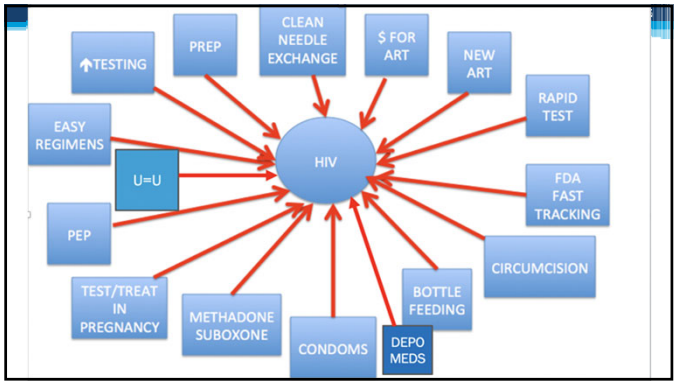

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