**Comprehensive Care Working Group: Organization of Services for Pregnant Women Living with HIV in a Jurisdiction** Distributed 3/23/2015

The following description of perinatal HIV service coordination was developed by the EMCT Stakeholders Comprehensive Care Working Group. The François-Xavier Bagnoud Center at Rutgers University School of Nursing provides technical assistance to the EMCT Stakeholders Group. Please submit any comments or suggested revisions to Mary Jo Hoyt ([hoyt@sn.rutgers.edu](mailto:hoyt@sn.rutgers.edu)).

**Perinatal HIV Service Coordination (PHSC)**

One strategy for achieving comprehensive clinical care for pregnant women with HIV infection is to establish a Perinatal HIV Service Coordinator (PHSC) in every US jurisdiction that would link HIV-infected pregnant women with appropriate services. Recognizing that jurisdictions may need to accomplish the activities outlined in a variety of ways, the workgroup noted that the functions could be incorporated into a specific position or could be distributed to a team that would be held accountable for the accomplishment of the functions.

The essential functions of PHSC coordination are:

1. Identify HIV-infected pregnant women before the end of the pregnancy in real time.
   1. A variety of methods may be used to detect cases, including (but not limited to):
      1. Lab-based reporting of pregnancy in HIV-infected women
      2. Lab-based reporting of HIV-infection among pregnant women
      3. Frequent direct contact with prenatal care providers
      4. Perinatal hotlines
      5. Surveillance data (when appropriate and allowed by law/regulation)
      6. Relationships with substance abuse, family planning and other providers
      7. Other methods as appropriate
   2. Ensure that every HIV-infected pregnant woman in the jurisdiction is known to the system prior to delivery, i.e., the system should cover the entire jurisdiction geographically and temporally.
   3. The PHSC should ensure that the system collects data regarding the care received by each woman (prenatal care, timing of testing during pregnancy, ARV receipt, mode of delivery) in a timely manner such that failures at any step of care can be addressed.
   4. Detection of an infant’s HIV exposure for the first time at or after delivery should be considered a systems failure and should be investigated thoroughly by the PHSC or through a fetal infant mortality review (FIMR)/HIV process.
   5. The PHSC should collaborate with traditional surveillance and intervention systems for HIV and other perinatal infections (e.g., perinatal hepatitis B, syphilis, DIS, etc.).
2. Document care received and missed prevention opportunities experienced by each HIV-infected pregnant woman in the jurisdiction and facilitate real-time linkages to care where needed.
3. Develop and maintain relationships with care organization including not only health care, but housing, substance treatment and WIC that will ensure that the woman is maximally engaged in care, including post-natal and family planning services.
4. Assure that detailed case reviews occur, at a minimum, for all perinatal transmissions and late diagnoses and that systems failures leading to missed prevention opportunities are addressed.
5. Aggregate and report cases and missed opportunities detected.