Zika and Enhancement of Birth Defects Surveillance: Tennessee Experience

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Tennessee Birth Defects System (TNBDS)

Integrated surveillance, case management, and linkage to services
- CDC US Zika Pregnancy Registry
- CDC Enhanced Microcephaly and Zika associated Birth Defects Surveillance
- Tennessee birth defects registry
  - TCA 68-5-506
Staring Point: Tennessee Birth Defects Registry
Established June 2000 (TCA 68-5-506)

- Annual report of birth defects prevalence and trends
- Determine possible association of environmental hazards and other potential causes of birth defects
- Evaluate current birth defect prevention initiatives
- Provide families of children with birth defects information on public services available

Limitations:
- Unfunded
- 18-24 month lag
- Based on hospital discharge data set
- Very limited capacity for linking datasets, following outcomes, connection to care, or prevention efforts

Rapid Evolution

Case Identification:
- Zika testing in pregnancy (January 2016)
- Provider report to RedCap web interface (microcephaly 2/16 evolving to neurologic birth defects 1/17)
- Eventual integration with birth file as secondary means of neurologic birth defect identification

Linkage:
- RedCap/vital records data fields to Neometrics case management system
- Data verification and completion by epidemiologist, linkage systems, nurse, administrative systems
- Generation of follow up protocols (clinical, early intervention, family peer navigator)
- Outcomes monitoring through nurse, follow up in EIS system for 3 years/up to age 5
Enabling Factors

Funding

• ELC M2: Epidemiologist
• Microcephaly/birth defects (CDC-DD16-1605): nurse consultant, admin/data support, IT and case management build out
• ELC Supplement: hospital reporting support, increased screening and referral capacity of provider network, educational and communications campaign, informatics

MCH :

• “Surge capacity” of informatics, newborn screening, CYSHC
• People, systems and infrastructure

Partnerships

• Informatics
• Education/Early Intervention Systems
• LEND
• Perinatal and genetics centers
• TNAAP
• Family Voices
• Hospital Association