Strategic Partnerships to Ensure a Comprehensive Public Health Surveillance System to Monitor Birth Defects

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Kentucky Public Health

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Background

- History
  - Funded through the CDC from 1999-2005 and 2010 to present.
  - KRS 211.655, KRS 211.660, KRS 211.665, KRS 611.670, and 902 KAR 19:010
- Methods
  - Passive surveillance with confirmation
  - Children ages 0 – 5 years seen at a Kentucky facility
  - Mandatory inpatient reporting, voluntary outpatient reporting
  - 8 reporting sources
  - Prior to October 2015, database maintenance was so substantial that it hindered other programmatic activities
**Phase 1 - Investigation**

- **Steps:**
  1. Identify others who have built databases
  2. Seek advice and input
  3. Build a wish list

- **Collaborations:**
  - NBDPN Guidelines for Conducting Birth Defects Surveillance
  - Illinois Adverse Pregnancy Outcomes Reporting System
  - Kentucky childhood lead prevention program
  - Kentucky newborn screening case management program

- **Results:**
  - List of essential attributes

**Phase 2 - Design**

- **Steps:**
  - Too many to list here!

- **Collaborations:**
  - Kentucky Office of Application Technology Services
  - University of Kentucky and University of Louisville genetics clinics
  - Genetics labs
  - Kentucky Hospital Association
  - Kentucky Newborn Screening Case Management Program
  - Public Health Neonatal Abstinence Syndrome Reporting Registry
  - Kentucky Office of Vital Statistics

- **Results:**
  - Fully functional database

**Phase 3 - Refinements**

- **Steps:**
  1. Sign formal agreements with partners
  2. Outline referral process and design tracking mechanism
  3. Create reports based on data-sharing needs
  4. Enhance case database features for case confirmation

- **Collaborations:**
  - First Steps Kentucky Early Intervention System
  - Office of Children with Special Health Care Needs
  - Environmental Public Health Tracking Network
  - Kentucky Health Information Exchange

- **Results:**
  - Enhanced database with case management and reports
Other Benefits

• System improvements:
  • More complete, accurate, and timely data
  • System is tailored to the needs of program staff
  • More automation has reduced manual effort

• Allowing KBSR to:
  • Produce reports, fact sheets, and data briefs
  • Facilitate academic collaborations and publications
  • Participate in national birth defects epidemiology studies
  • Identify gaps in services for partner service agencies
  • Inform data-driven prevention efforts

Conclusion

• Partnerships are essential in:
  • Learning from peers
  • Establishing needs, barriers, and assets
  • Serving families

• However,
  • Formal agreements move slowly
  • Partnerships can be expensive

Thank you!
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