Rhode Island Birth Defects Program
Outline

• Overview of Rhode Island Birth Defects Program
• Rhode Island Context
• Program Elements
• KIDSNET
• Case Ascertainment
• Service Assessment/Quality Assurance
• Case Management and Referral
• Opportunities
Birth Defects Program
Overview
Goals and Objectives

• Describe the occurrence of birth defects in children up to age five

• Detect trends of morbidity and mortality

• Identify children with birth defects to intervene on a timely basis for treatment
Goals and Objectives

• Assure children with birth defects receive the services they need:
  – Quality Assurance
  – Medical Home
Program Staff

• Primary Staff:
  – Program Manager
  – Epidemiologist/Data Manager
  – Parent consultant

• Advisory Committee (~15):
  – March of Dimes
  – Regional Perinatal Center
  – Hasbro Children’s Hospital
  – Rhode Island KIDS COUNT
  – Parents
  – Community Practice Physicians
  – Visiting Nurse Agencies
Rhode Island Context
Rhode Island Context

• ~12,500 births among RI residents annually
  – ~650 with birth defects (ICD-9-CM codes: 740-759.9)

• 7 maternity hospitals, including:
  – Women and Infants Hospital
    ✓ Regional perinatal center
    ✓ Represents 68% of all births among RI residents
    ✓ Prenatal Testing and Specialty Clinic
    ✓ Prenatal Diagnosis Center (PDC)

• RI Hospital Child Neurodevelopment Center
  – Specialty clinics and services for children and young adults with special health care needs
Rhode Island Context

• Newborn Developmental Risk Screening (NDRS) Program:
  – All babies born at Rhode Island maternity hospitals are screened for developmental risk factors using criteria set
  – Babies determined to be at risk are offered service referrals and home visits
  – NDRS data are electronically submitted to the Health Department
Rhode Island Context

Timeline

• 2000: HEALTH received a cooperative agreement from the CDC to develop a birth defects surveillance system

• 2003: Legislation passed mandating a birth defects surveillance and information system

• 2005: Rules and Regulations Pertaining to Rhode Island Birth Defects Registry

• 2005-2010: Current cooperative agreement cycle (~$160,000 per year)
Program Elements
Methodology

- All births with birth defects diagnostic codes are identified using hospital discharge data (HDD) and are entered into the Birth Defects database

- Data are linked to KIDSNET, Rhode Island’s integrated child health information system, to track cases for service utilization

- A set of sentinel conditions have been identified and will be the focus for outreach and referral
KIDSNET Mission

To facilitate the collection and appropriate sharing of health data with healthcare providers, parents, maternal and child health programs, and other child service providers for the provision of timely and appropriate preventive health services and follow up.
KIDSNET Functions

• Links health and service care providers to Department of Health

• Facilitates sharing of information between authorized users providing services

• Promotes comprehensive contacts with families
System Features and Design

- Includes all RI births from January 1, 1997
- Originally, dial in access by users--now web-based
- Only immunization data come directly from providers
- Follow-up and QA components
KIDSNET Affiliated Programs

6 Universal:
• Newborn Developmental Risk*
• Newborn Bloodspot Screening
• Newborn Hearing Assessment
• Immunization*
• Childhood Lead Poisoning
• Vital Records

4 Targeted:
• WIC
• Early Intervention
• Family Outreach (Home Visiting)*
• Birth Defects

*Fully integrated databases
KIDSNET Users

• Health department staff
  ➢ KIDSNET affiliated programs
• Primary care providers
• Contracted Agencies (Home Visiting, WIC)
• Head Start Agencies
• Lead Centers
• School Nurse Teachers
• Audiologists
• Managed Care Organizations
• Community-Based Organizations
Ascertainment, Assurance and Referral Systems
Case Ascertainment Sources

- Hospital Discharge Data
- Hospital Direct Reporting
  - Medical Record Abstraction
- Child Neurodevelopment Center
- Genetics Counseling Center
Case Management System

NDRS → KIDSNET

SENTINEL CONDITIONS

CASE MANAGEMENT/REFERRAL

Genetics Counseling Center
Child Neurodevelopment Center

Family Outreach Program/Home Visiting

Pediatric Cardiology
Pediatric Surgery
Other Specialty Services

Program Services (e.g., Early Intervention)
Service Assessment

• Determine the following:
  – Are patients receiving optimal care?
  – Are services provided in a timely manner according to guidelines?
  – Are patients/families satisfied with care?
  – Are health care providers satisfied with system of care?

• Conducted focus groups and surveys with:
  – Families
  – Health care providers
Service Assessment

Tools
• National Guidelines (recommended services by age intervals)
  – Pilot: Down syndrome
• Referrals for family support, education, etc

Perspectives:
• Family
• Physician

Data Collection Methodology (PPEP)
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Activities and Opportunities
Activities and Opportunities

• Coordinate with existing initiatives

• Continue to determine whether children with birth defects and their families have access to comprehensive, coordinated, community-based care

• Disseminate data and collaborate with community partners/stakeholders

• Educate families and providers regarding programs and services for children with birth defects
Activities and Opportunities

• Focus Groups and Interviews

• Service Assessments

• Education and Awareness
  – Grand Rounds/Forums
  – Data Book
  – Brochures

• Collaborative Research Projects
Challenges

- Funding
- Staffing
- State Constraints
- Visibility
- Reporting
Samara Viner-Brown, MS
Chief, Center for Health Data and Analysis
401-222-5935
samara.viner-brown@health.ri.gov
www.health.ri.gov