



Improving Perinatal Data— the State Perspective

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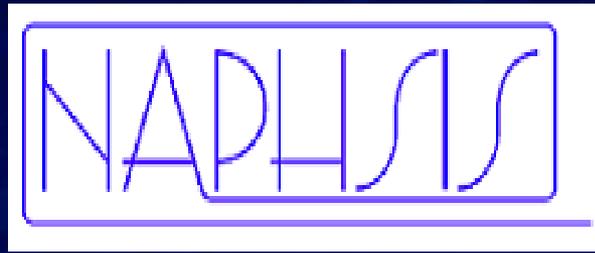
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Vital Statistics

- What are they?
- What's right?
- What's wrong?
- What can we do?



- Representing states on behalf of NAPHSIS
 - National Association for Public Health Statistics and Information Systems
 - Association of state vital records and public health statistics offices representing 50 states, 5 U.S. territories, NYC and D.C.
 - Mission: To provide national leadership to improve public health information through strengthening and integrating vital records, health statistics and other health information.

Vital statistics

- Data relating to births, deaths, marriages and divorces
- Three systems
 - Civil registration system
 - Records management system
 - Public health data system

How are vital statistics collected?

- State function
- Recording of vital events is the responsibility of the jurisdiction in which the event occurs
 - 50 states
 - 5 U.S. territories
 - NYC
 - DC

Contracts to provide data to federal agencies

- NCHS
- SSA
- CPSC
- NIOSH

What's right with vital statistics?

- Critical source of public health data
- (Just about) complete reporting
- (Mostly) consistent data among jurisdictions

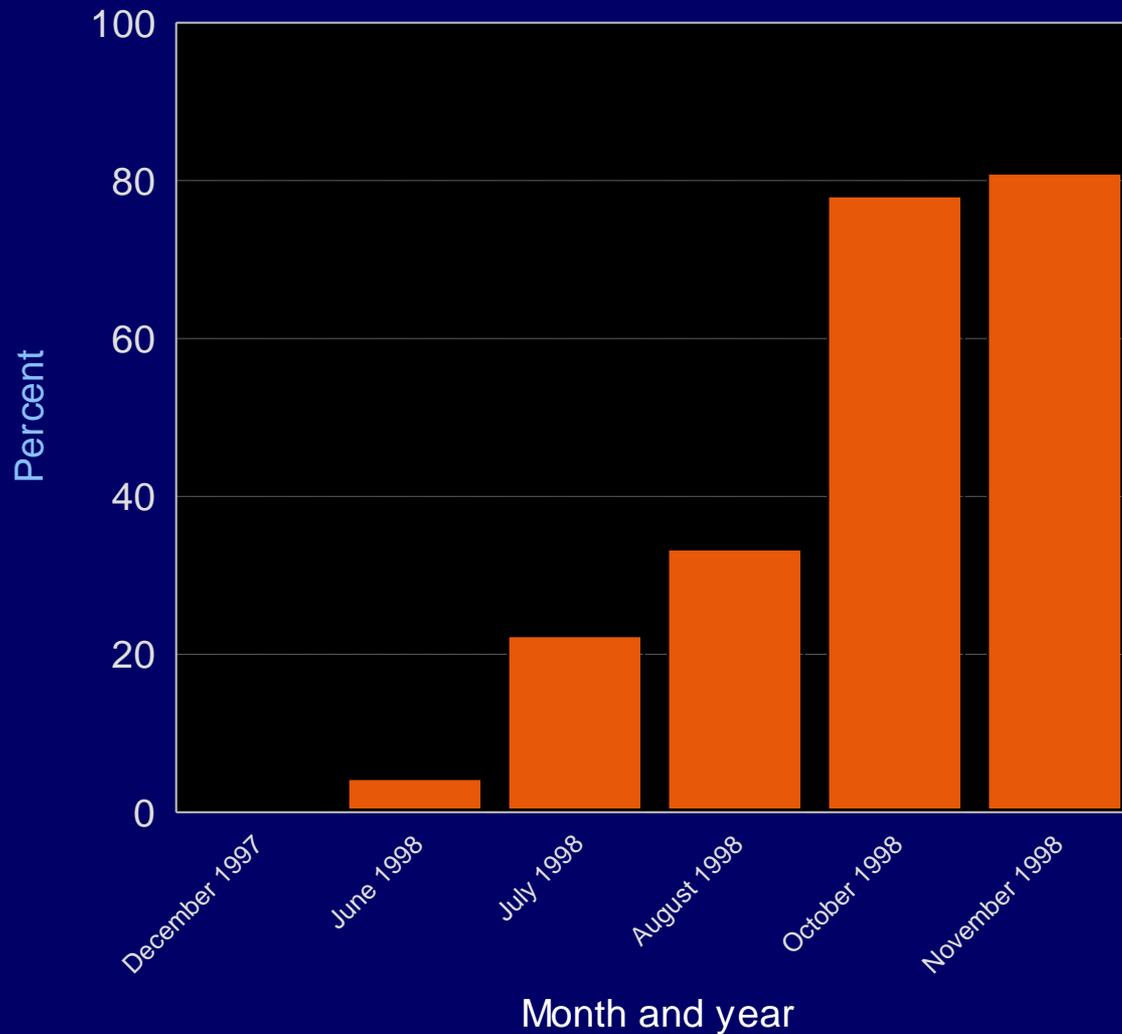
What's wrong?

- Data quality
- No standard national data set
- Underutilized
- Antiquated data systems

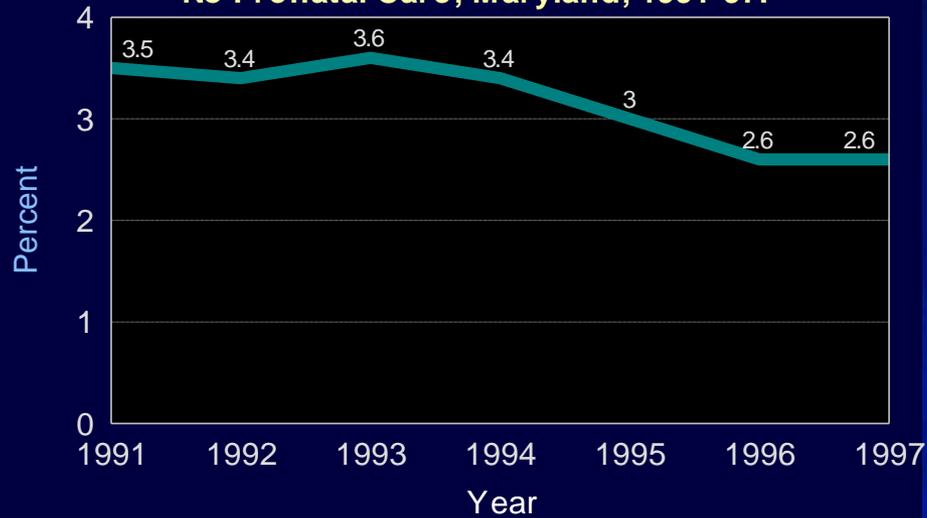
What's wrong?

- Data quality
 - Timeliness, completeness, accuracy
 - Poor reporting of certain events

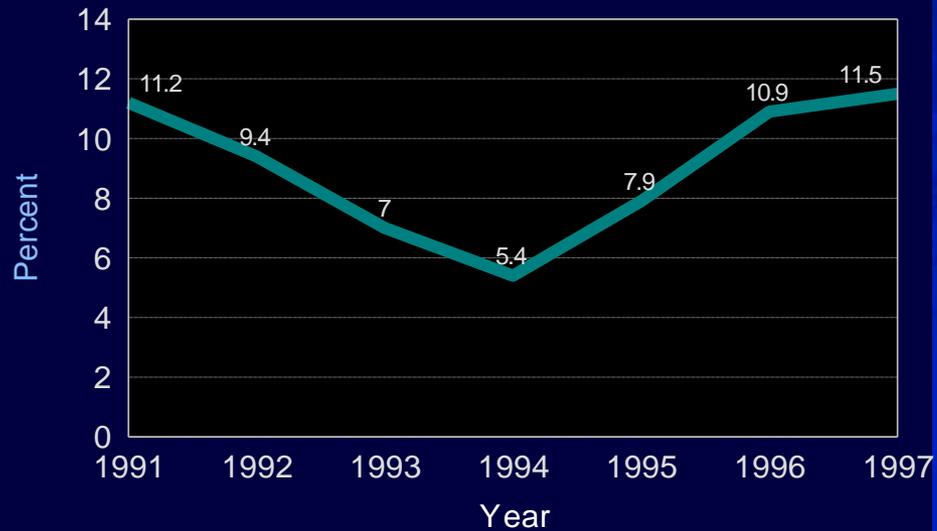
Percentage of Birth Certificates Filed Within 72 Hours of Birth, Maryland, Selected Months, 1997-1998.



Percentage of Births to Women Who Received Late* or No Prenatal Care, Maryland, 1991-97.



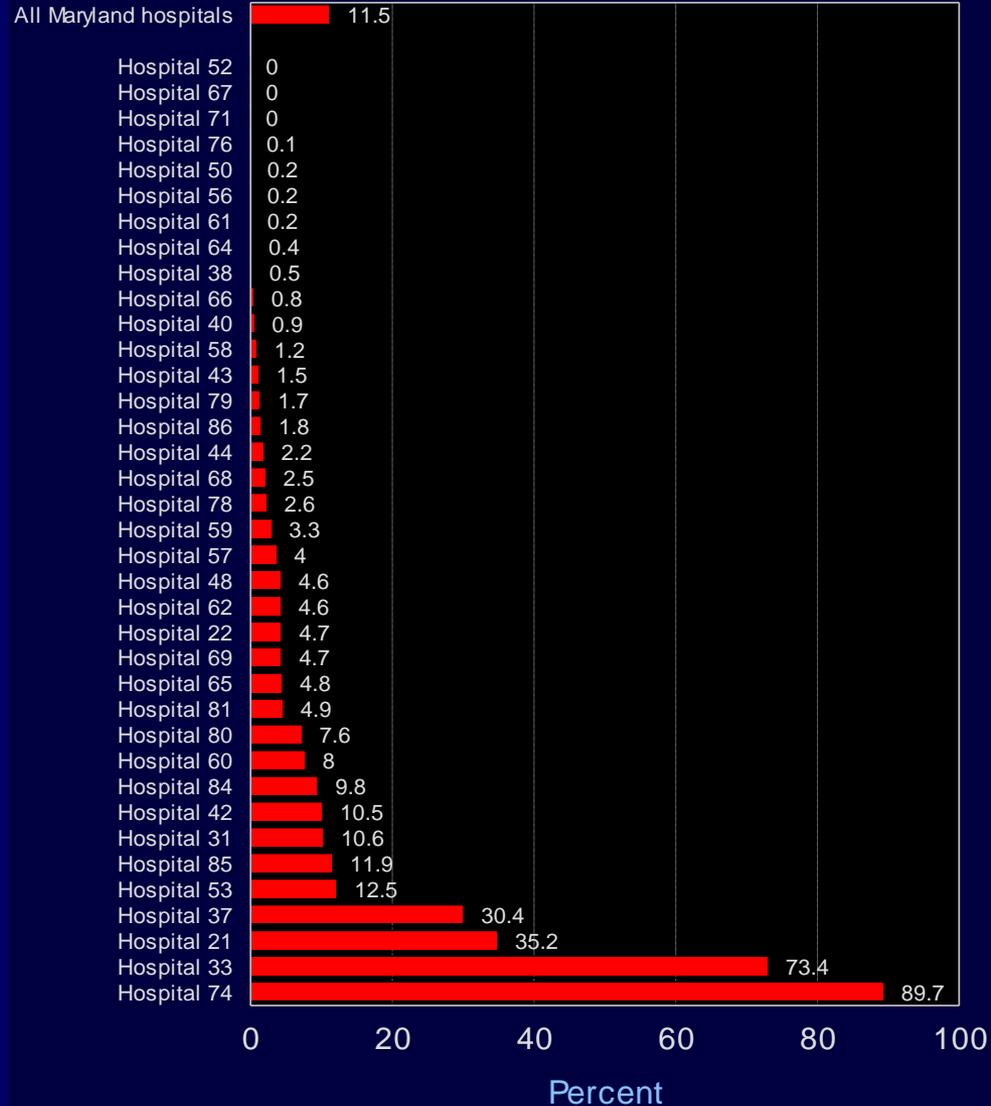
Percentage of Birth Certificates With Incomplete Prenatal Care Information, Maryland, 1991-97.



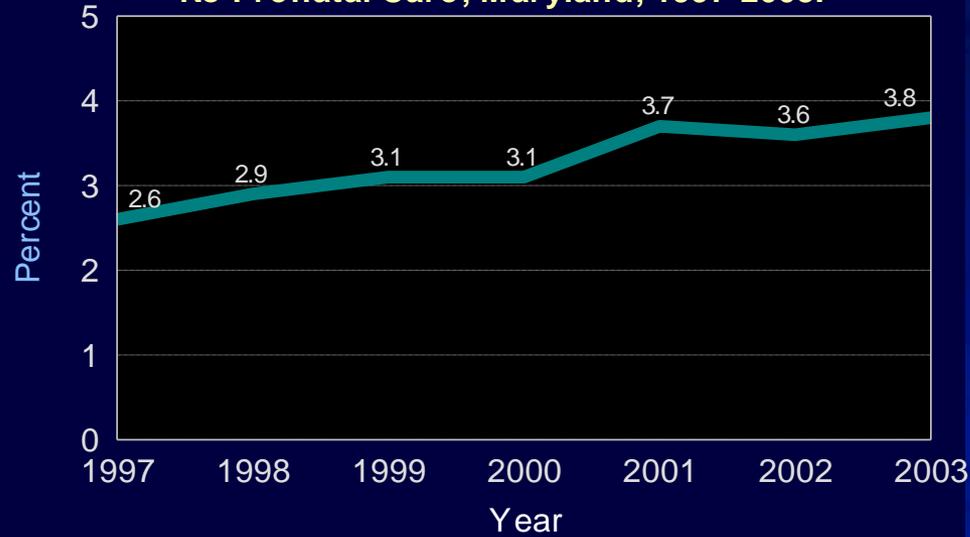
*Care beginning in the third trimester

Percentage of Birth Certificates Missing Information on the Month Prenatal Care Began

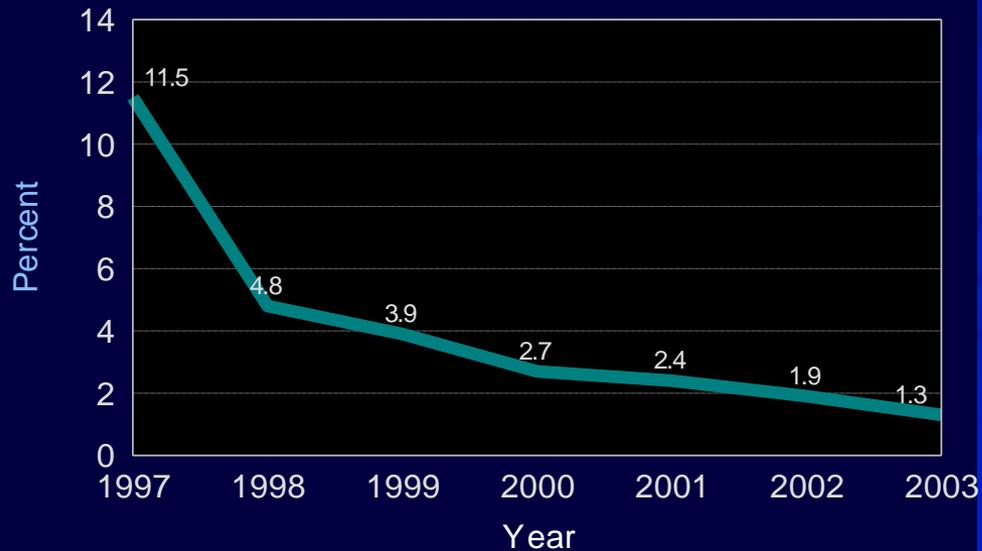
December 1997 Births



Percentage of Births to Women Who Received Late* or No Prenatal Care, Maryland, 1997-2003.



Percentage of Birth Certificates With Incomplete Prenatal Care Information, Maryland, 1997-2003.



*Care beginning in the third trimester

Efforts to improve perinatal data in Maryland

- Monthly report cards
- Medical record audits
- Fetal/infant death field staff

What's wrong?

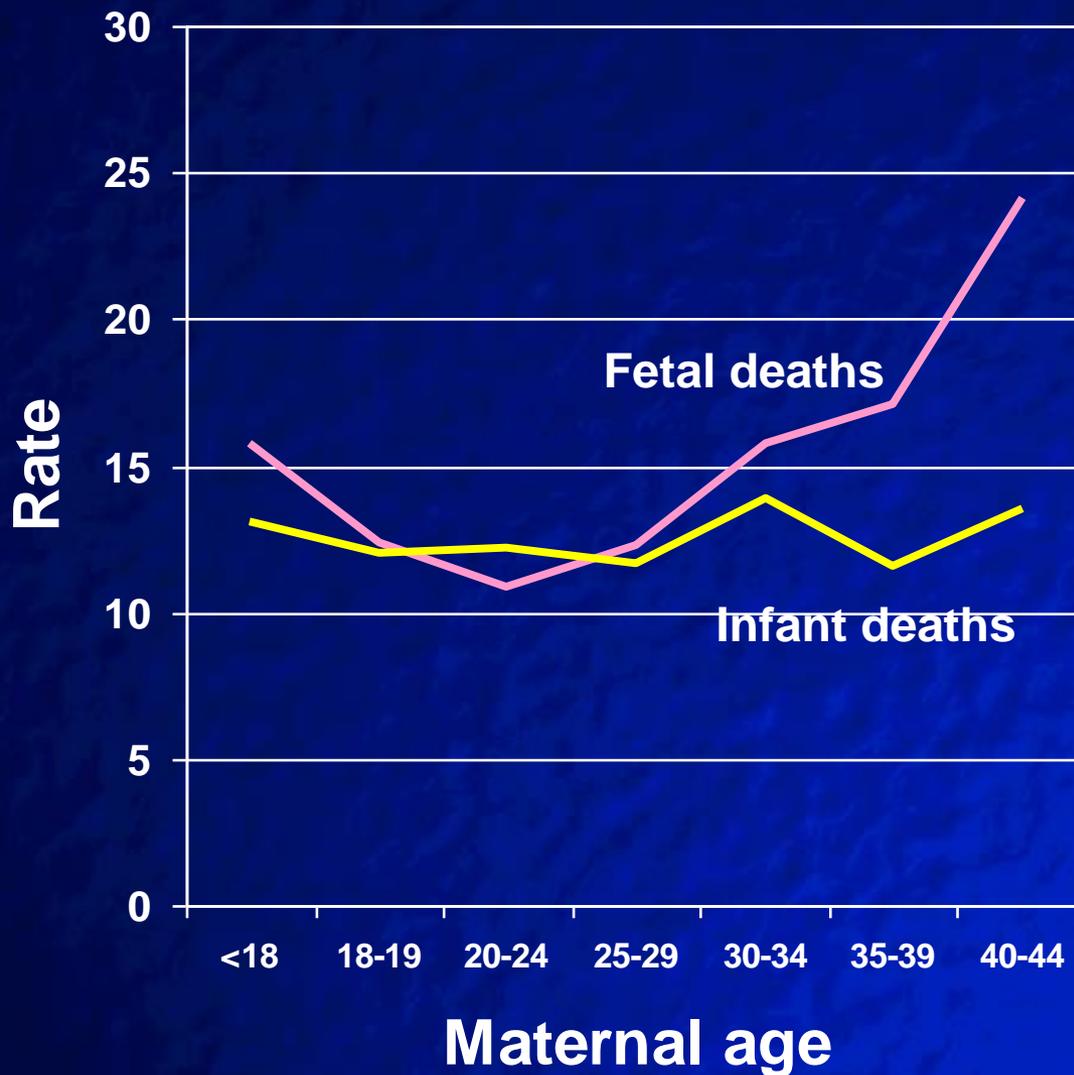
- Data quality

- Timeliness, completeness, accuracy
- Poor reporting of certain events
 - Fetal deaths
 - Early infant deaths

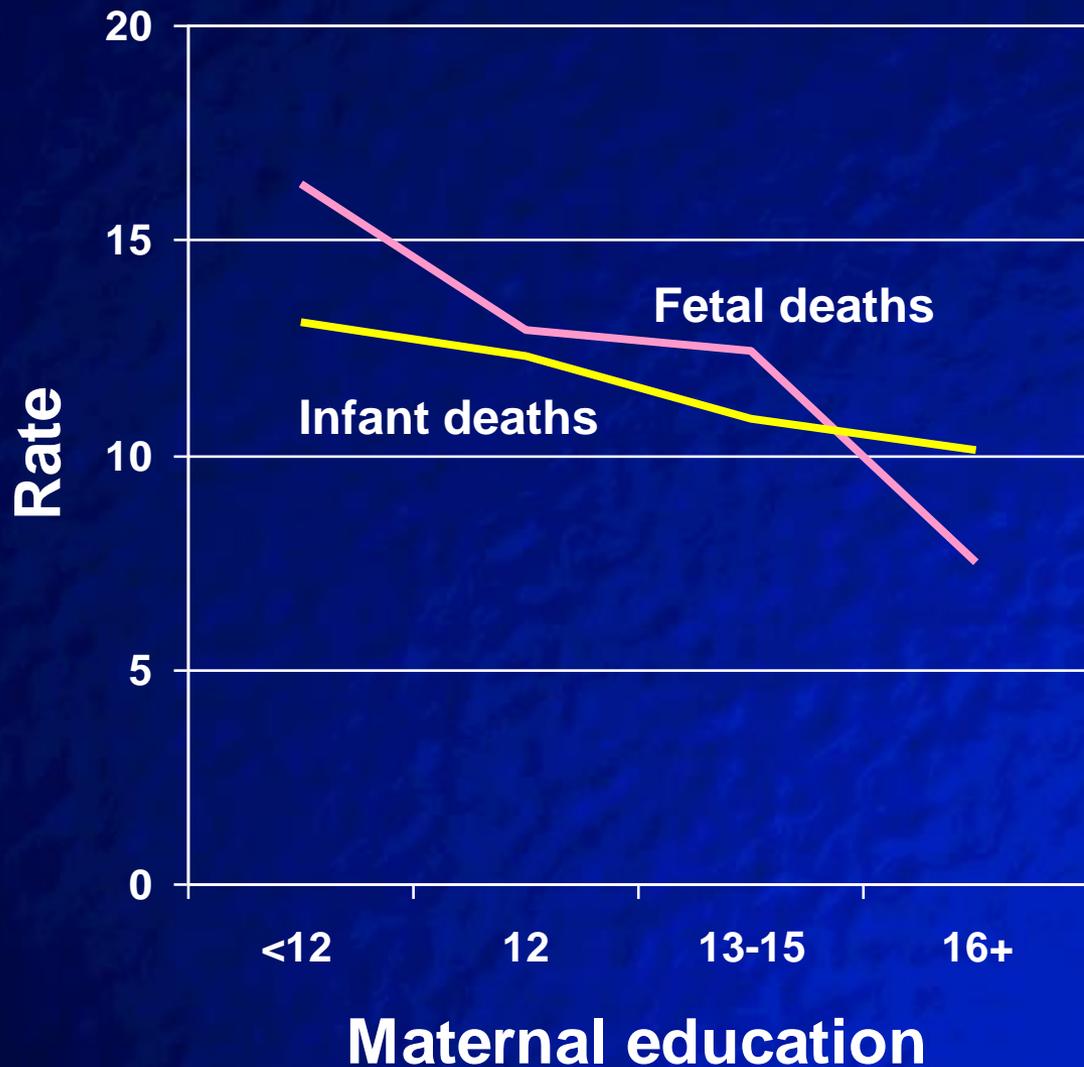
Poor fetal mortality data

- Poorly collected and reported in many jurisdictions
- Improved Maryland data showed:
 - More fetal deaths than infant deaths
 - Misclassification of fetal/early infant deaths
 - Trends differ for fetal and infant deaths

Black Fetal and Infant Mortality Rates by Maternal Age, Maryland, 2000-2002.



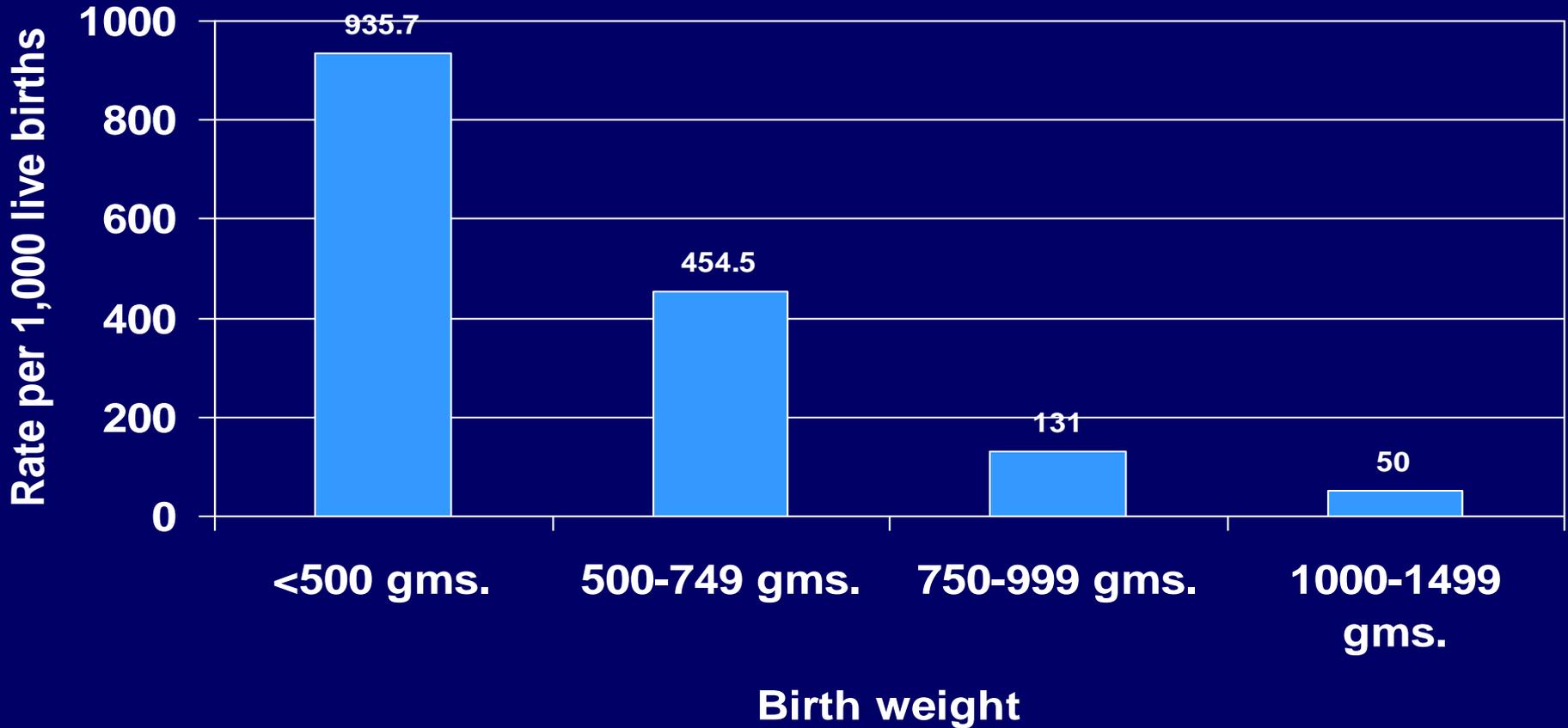
Black Fetal and Infant Mortality Rates by Maternal Education, Maryland, 2000-2002.



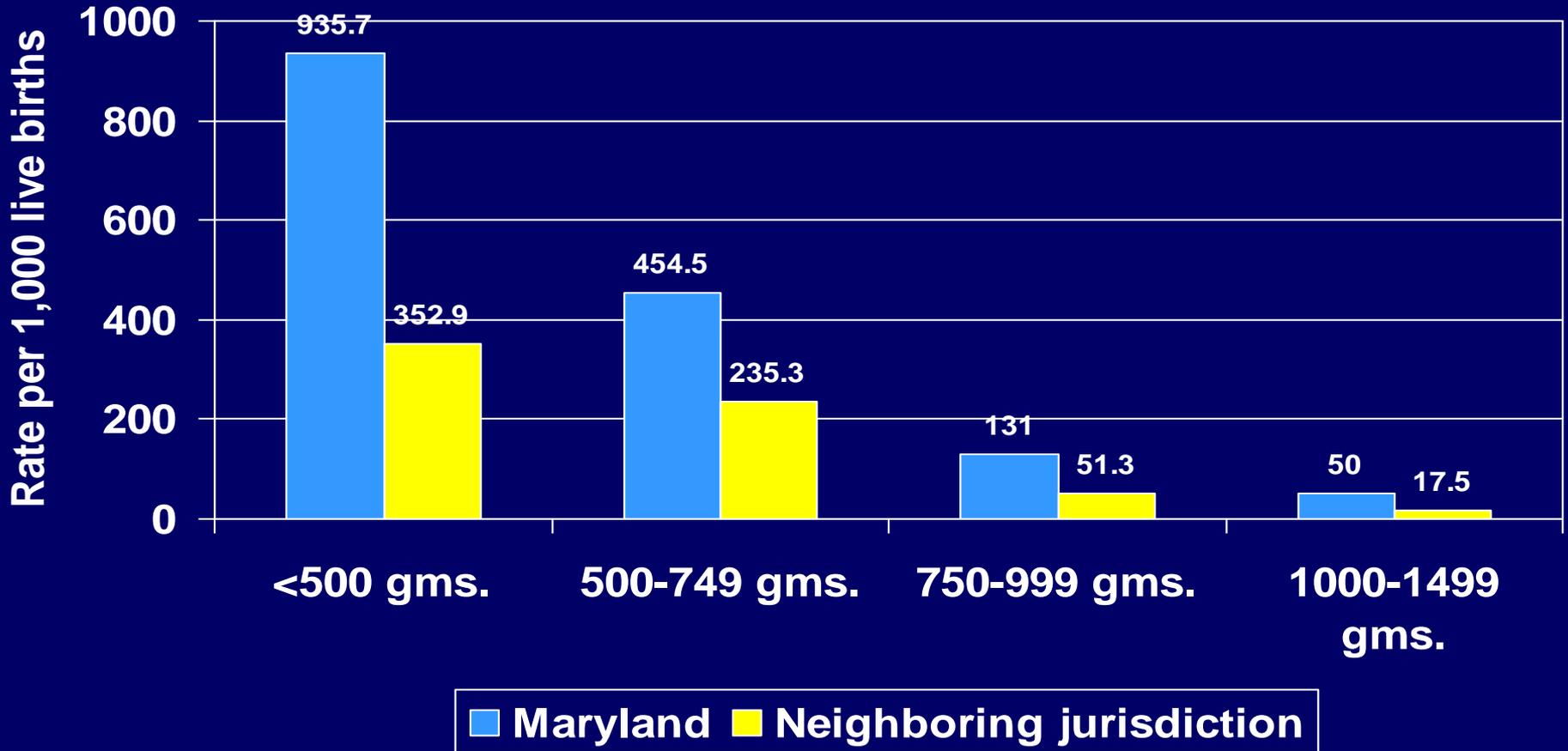
Poor reporting of infant deaths at early gestations

- Contract with NCHS requires states to:
 - Link every infant death record with a corresponding birth record
 - Follow up of all live born infants with birth weights <750 grams

Infant mortality rate by birth weight, Maryland, 2002.



Infant mortality rate by birth weight and place of delivery



What's wrong?

- Data quality
 - Timeliness, completeness, accuracy
 - Poor reporting of certain events
- No standard national data set

Revised U.S. Standard Birth Certificate

New items	Modified items
<ul style="list-style-type: none">■ Fertility therapy■ WIC during pregnancy■ Infections during pregnancy■ Maternal morbidity■ Breast feeding■ Source of payment for the delivery	<ul style="list-style-type: none">■ Race and education of parents■ Cigarette smoking■ Prenatal care■ Method of delivery■ Congenital anomalies

Revised U.S. Standard Fetal Death Certificate

New items	Modified items
<ul style="list-style-type: none">■ Fertility therapy■ WIC during pregnancy■ Infections during pregnancy■ Maternal morbidity■ Source of payment for the delivery	<ul style="list-style-type: none">■ Race and education of parents■ Cigarette smoking■ Prenatal care■ Method of delivery■ Congenital anomalies■ Cause of death

What's wrong?

- Data quality
 - Timeliness, completeness, accuracy
 - Poor reporting of certain events
- No standard national data set
- Data are underutilized
 - Traditional role was to collect data for statistical reports for state and federal agencies
 - Need to expand functions

Vital statistics—~~3~~ 4 systems

- Civil registration system
- Records management system
- Public health data system
- Public health surveillance system

Data surveillance system

- Vital records systems should evolve into perinatal data surveillance systems
 - Should allow states to monitor trends as data are collected
 - Should allow states to identify problems in real time
 - Immediate identification of areas with high rates of anomalies, infant deaths, etc.
 - Tracking of at-risk infants
 - Should allow for the collection of additional perinatal data
 - Should allow for routine linkage with other data sets

Expanded use of data needs to happen at the state level

- Only states collect data from the source
- Only states have identifiers
- Only states have access to other data sets

What's wrong?

- Data quality
- No standard national data set
- Underutilized at state level
- Antiquated data systems

Consequences of antiquated data collection systems

- Limit efforts to improve data quality
- Create difficulties in moving to revised certificates
- Limit efforts to expand uses of data

History of reengineering

- States knew they had to update systems
 - Systems were antiquated
 - Needed to implement revised standard certificates
- Early attempts were often unsuccessful

‘Every man for himself’ approach wasn’t working

- Repetitive costs
 - Dollars
 - Human resources
 - Time
- Lack of technical resources in states
- High risk borne by each state individually
- Failed to build on collective expertise of states

Reengineering strategy

- Development of a national, model vital statistics system
 - Collaborative effort of NAPHSIS, NCHS, SSA
 - Project teams produced conceptual framework for building models
 - Goal: the development of state-specific systems that use the same standards to record the same information in the same manner by adhering to the same business rules
 - Standardized system concept that would meet at least 85% of the reengineering needs of any jurisdiction

Benefits of collaborative effort to create a national model

- Greater probability of success
 - Shared expertise and best practices
- Faster implementation
- Significantly lower costs
 - Dollars to states
 - Human resources

What will reengineered systems allow us to do?

- Collect better quality data
 - More timely
 - More complete
 - More accurate
- Uniformly employ national standards
- Implement revised certificates/data sets
- Enhance the role of vital statistics as a surveillance system

South Dakota Electronic Vital Records and Screening System

- Web-based system collects:
 - Vital records data
 - Metabolic screening data
 - Hearing screening data
 - Immunization data
- Results
 - Improved timeliness, completeness and accuracy of vital records data
 - Automatic linkage of vital record data with metabolic screening, hearing screening and immunization data
 - Immediate identification of unscreened infants
 - Substantial increase in percentage of screened infants

Reengineering—where are we?

- Functional requirements for birth and death registration have been established
- Have national model; being implemented in selected states
- Lack of funding to complete process

What is our vision?

- Collection of timely, complete, accurate data
- Reengineered, web-based data collection systems that would allow for:
 - Immediate electronic transfer to state vital records offices
 - Immediate transfer to other health dept. programs (immunization registries, hearing screening, birth defects)
 - Timely transfer of out of state data
 - Timely sharing of data with federal partners
- Immediate linkage of birth and infant death data
- Linkage with other data sets
- Continued evolution from 'vital registration system' to 'surveillance system'

Summary—what do we need to be successful?

- \$\$\$ for reengineered systems based on the national model in all states
- \$\$\$ to implement revised certificates in all states
- \$\$\$ to improve data quality
 - National training coordinating center
 - Technical assistance to states to improve collection and analysis of perinatal data
- NAPHESIS wish list:
 - Support to continue reengineering work
 - Support to develop a national training coordinating center
 - Support to provide technical assistance to states to improve data quality

**For more information about NAPHSIS and/or the
reengineering effort, contact:**

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