

# Data Sharing



Center for Medicaid & State Operations/CMS

Center for Health Services Research and Policy  
George Washington University

*February 11, 2003*

## **Purpose**

- **Identify key facilitators and barriers in state agency data sharing activities**
- **Specific areas of investigation included:**
  - **Administrative and organizational features associated with the development and implementation of data sharing activities**
  - **Operational (systems, programs, staffing, supplies) characteristics and resources.**
  - **Legal factors (federal and state) influencing *data sharing activities***

## **States Visited**

- **Rhode Island**
- **South Carolina**
- **Utah**
- **Kansas**
- **Wisconsin**

## **Rhode Island**

- **Community Access Program Grant**
- **Prevention and Amelioration of Child Lead Poisoning**
- **Medicaid Research and Evaluation Project**

## **Utah**

- **Statewide Immunization Information System (USIIS)-- registry**
  
- **Data Warehouse**

## **Wisconsin**

- **Wisconsin Immunization Registry**
- **Lead Screening Project**
- **Milwaukee Asthma Prevention Project**
- **Linked Birth Events and WIC/Prenatal Care Coordination Programs**

## South Carolina

- **MCH Evaluation Program**



- **Integrated Data System - Office Research + Statistics (ORS)**

# **Kansas**

- **Immunization Registry**
- **Medicaid/ADAP Coordination**
- **Children with Special Health Care Needs**
- **Long-term Care - MDS/OASIS**

## **Nature of Data Sharing Activities**

- **Internal Medicaid Program Activities**
  - *Eligibility and claims history files supplemented by public health data bases*
  - *Data are not shared; results may be*
- **Interagency activities between Medicaid and public health programs**
  - *Medicaid files linked to public health*
  - *Data are shared, joint analysis, joint dissemination*

## **Nature of Data Sharing Activities**

- **State and Provider partnerships**
  - *Medicaid files linked to clinical data generated by community healthcare providers and reported through public health system*
  - *“Real time” access to linked data*
- **State and academic partnerships**
  - *Medicaid files linked to public health databases*
  - *Academic researchers helping to design studies and analyze results*

## **Administrative Issues**

- **Origin and Development**
- **Implementation and Management**
- **Resources and Other Support**

## **Development -- Facilitators**

- **Originating Event -- Varied; high priority**
- **Shared Interagency Vision and Goals -- public health perspective incorporated into planning (senior and program staff)**
- **Willingness to and support of “thinking outside the box”**
- **History of data sharing activities and MIS**

## **Development -- Facilitators**

- **Planning Committee -- Inclusive of user groups and operational needs of programs (not research)**
- **Plan -- Clear roles and responsibilities; established agreements (MOA, etc)**
- **Sufficient planning and start-up time**
- **Resources -- Substantial external (CDC, RWJ, HRSA) and internal in-kind support**

# Implementation and Management

- **Steering Committee-- Interagency and external users; broad responsibilities and shared vision**
- **Leadership--Senior administrators with direct interaction with IT staff**
- **Research capacity -- Reliance on consultants, academic institutions, other agencies**



## **Implementation and Management**

- **Accessing Data Sets -- Shared responsibilities and timeliness; federal-state issues**
- **Program Use -- Multidimensional and cross-population; sufficient for program needs**
- **Temporality of Linked Data Bases -- One-time-only linkages to answer a question versus maintenance of linked data base as an ongoing resource**

# **Implementation and Management**

- **Data Linkage Mechanisms -- range from rudimentary to sophisticated, even in the same state system**
  - ***Use of proprietary linkage software algorithms***
  - ***Development of in-house algorithms using SAS or other applications software***
  - ***Some, but not all, states, have tested their linkage algorithms***



# Implementation and Management

- Initial data linkage successes likely to lead to other joint Medicaid-public health applications



# Implementation and Management

## ● Resources

- *Sustainable and flexible (based on functionality)*
- *Use of computing systems - maximizing availability of upgraded systems purchased for MMIS management*
- *In-kind personnel is common, hiring of dedicated staff is not as common*
- *In-kind resources from MMIS contractors*
- *Long-term resources identified as in jeopardy due to state budget priorities or decreases in state budget*

## ***Data Sharing: Medicaid and Public Health***

- **Governance mechanisms may already exist or be put in place by work groups or user groups**
- **Originator of the primary data base perceived as the “owner” or custodian -- their security policies commonly used to allow access to the data**
- **Standard confidentiality and security mechanism in place -- centralized versus delegated**
- **Public use data bases not common**

# **Impact and Benefits**

- **Service Delivery --quality/performance improvement**
- **Policy making**
- **Legislative Reporting**
- **Reports/Publications**
- **Data Warehouse**
- **New Initiatives**
- **Learning Experience**

## **Overall Conclusion re Benefits**

- **Alignment of Medicaid and Public Health agency goals and efforts increases efficiency and effectiveness of BOTH agency programs**



# **Legal Analysis -- Overview**

- **The legal analysis was fairly consistent among all states visited**
- **There was no major variation in legal findings based on state, agency structure or projects reviewed**
- **Overall, legal issues did NOT present significant hurdles in data sharing projects**



## **Legal Analysis -- Key Findings**

- **Most significant barrier: Medicaid confidentiality requirement which restricts use of information concerning applicants or beneficiaries to “purposes directly connected to the administration of the plan”**
  - ***Section 1902(a)(7) of the Social Security Act***



## **Legal Analysis -- Key Findings**

- **All states have a state confidentiality statute that mirrors the federal requirement**
- **Little guidance is available to determine what is “directly connected” to plan administration**



## **Legal Analysis -- Key Findings**

- **Other than state confidentiality statutes, there were few state laws that restricted ability to conduct data sharing activities**
- **Legal staffs were very cautious about sharing identifiable information**
- **HIPAA raised many concerns about confidentiality and admin burdens, but it was too early in the HIPAA implementation process for the states to know the extent of the impact at the time of the study**



# **Legal Analysis -- Key Findings**

- Usually, there was little formal interaction among staffs of various agencies.
- The lawyers did not indicate that the process was a barrier to developing data sharing projects and worked together as needed
- Data sharing projects were usually based on an MOU or Inter-Agency Agreement that clearly delineated each agency's role and which agency housed the data