

The National Electronic Disease Surveillance System (NEDSS):  
A standards based approach to connect public health and clinical medicine

Presentation for Childhood Lead Surveillance Meeting

St. Petersburg, Florida

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Mike Donnelly



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Limitations of current surveillance systems

- Multiplicity of categorical systems
- Data incomplete, often not timely
- Burden on respondents in health care sector increasingly unacceptable
- Systems do not utilize state of the art information technology
- NEDSS transforms state surveillance by:
  - Current data collection integrated and over the web
  - Automatic input from existing electronic databases



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Current Opportunities

- Progress in technology, informatics concepts
- National standards for health electronic data interchange with HIPAA '96
- Funding for National Electronic Disease Surveillance System (NEDSS)
  - FY2000 \$20 million, FY2001 \$27 million,
  - FY2002 \$27 million



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## NEDSS Vision

- To have integrated surveillance systems that can transfer appropriate public health, laboratory, and clinical data efficiently and securely over the internet
- Allow the gathering and analysis of information quickly and accurately
- Improve ability to identify outbreaks, monitor disease trends, identify and track emerging infections, recognize/respond to potential bioterrorism attacks



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## NEDSS Principles

- Utilization of industry standards
- Reliance on off-the-shelf software
- Internet-based secure transmission of data
- A common “look and feel” of systems
- No requirement to use specific software



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## NEDSS Systems Architecture

- Brings structure, standards and interoperability to the information systems elements of surveillance – not another system - a way for many to build interoperable systems
- Provides a structure around which CDC systems can be integrated
- Allows the latitude for states and local health departments to do specific implementations and fulfill public health needs
- Is respectful of local / state / federal data flow issues
- Facilitates the ready exchange of comparable data and reports between public health organizations without reprogramming



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## NEDSS “at-a-glance”

- NEDSS is a broad initiative using national data and information system standards for development of efficient, integrated, and interoperable surveillance systems at the state and local levels
- Includes tools for electronic data transfer to health department from health care system
  - e.g. from multi-jurisdictional clinical labs
- Security standards (HIPAA compliant) to maintain public health track record in protecting sensitive data
- Starts with focus—infectious disease—but keeps big picture in mind



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Implement an integrated data repository

- able to be patient centered, non-categorical



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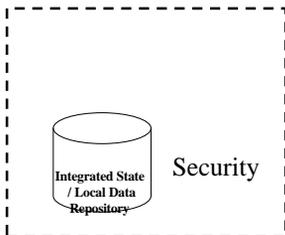
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Implement a security system and appropriate security policies (Internet-based, with a firewall and certificates or tokens)



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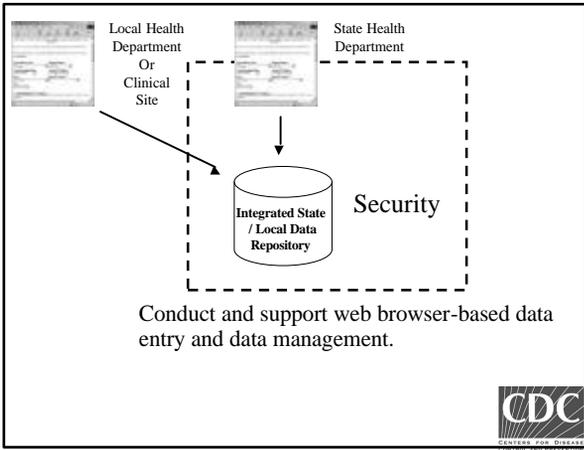
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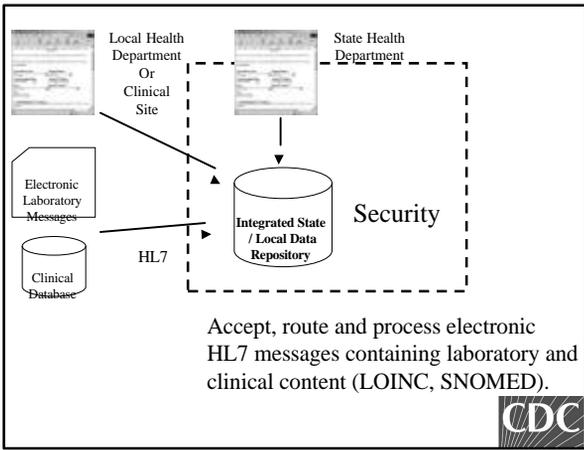
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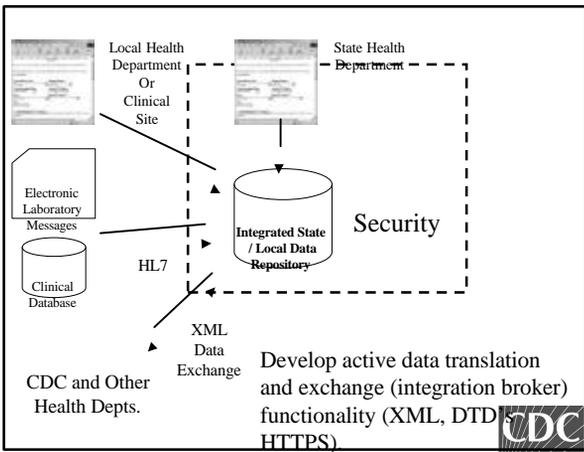
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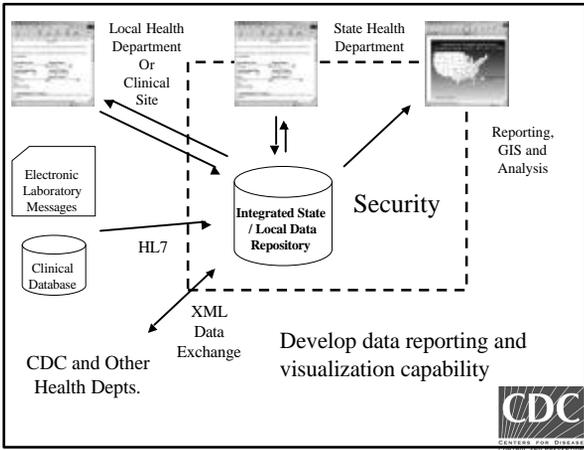
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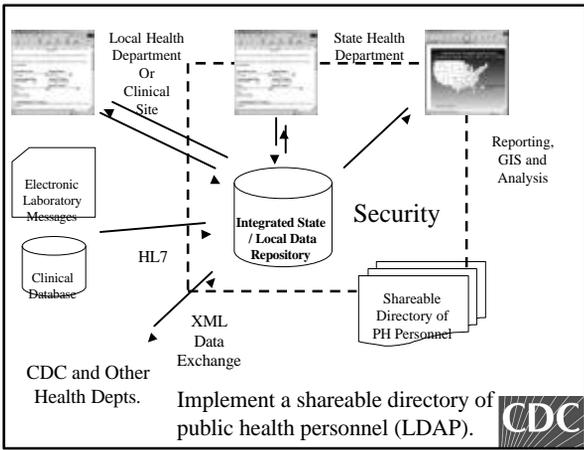
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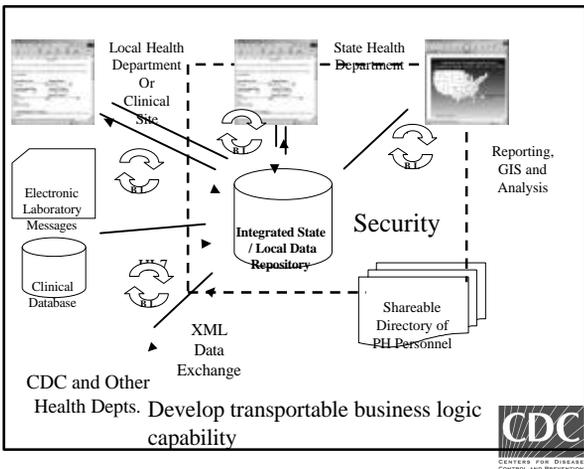
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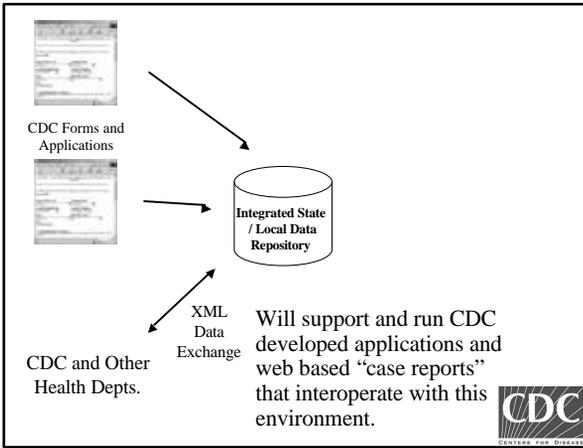
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### State "Base System" Option

**A NEDSS compatible system for state use developed by an experienced web software developer (Computer Sciences Corporation)**

- "Base system" includes Core Demographics and Nationally Notifiable Disease Module; person based Integrated Data repository; HL-7 messaging
- First Production Release of NEDSS Base System scheduled for completion September 30 – will include electronic lab reporting capability
- Base system is platform for other modules (PAMs)
- States have option to use (or not) CDC developed modules

**CDC**  
CENTERS FOR DISEASE CONTROL AND PREVENTION

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### NEDSS Base System and Program Area Modules

- Core Investigation Functionality (approximately 65 diseases)
- Extended Investigation Functionality (PAM's – Program Area Modules)
  - Hepatitis
  - Bacterial Meningitis and Invasive Respiratory Diseases
  - Vaccine Preventable Diseases

**CDC**  
CENTERS FOR DISEASE CONTROL AND PREVENTION

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## Program Area Module Development Phased Process

- Initial Design Specification
- Requirements Development
- Design Prototype
- Beta Testing
- Production Implementation
- New NEDSS PAM Task Order imminent – award October 2002



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## Additional Collaboration in NEDSS

- Partner organization “point of contact” & coordination, IT Committees (ASTHO, NACCHO, CSTE, APHL, NAPHSIS, NAHDO)
- State and local health department participation in developing NEDSS Base System
  - Joint Application Development (JAD) sessions
  - Ongoing review of requirements drafts, prototypes
- Collaboration with e Health Initiative, LabCorp, Quest
- Web Board conferences, postings



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## NEDSS Extra-mural Activities

**Assessment and Planning** – Assess current information systems personnel and technical infrastructure, evaluate that infrastructure against the NEDSS systems architecture and develop plans to migrate to the NEDSS architecture as needed.

**Element Development** – Implement between one and four of the NEDSS system architecture elements and use in the setting of identified public health activities.

**Charter Sites** - Conduct activities to implement and demonstrate the fully described systems architecture.



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## Current Status of NEDSS

- 50 states, 6 cities, and 1 territory funded for NEDSS: 43 started with Assessment & Planning phase in 2000
- September 2001: 35 states and 1 city receiving funds for development of NEDSS compatible systems
  - 16 implementing NEDSS compatible state developed system
  - 20 deploying NEDSS Base System (NBS)
- January 2002: Public Health and Social Services Emergency Fund (Emergency and Bioterrorism Preparedness) provides major funding for state and local public health capacity, including guidance from HHS on surveillance and IT capacity



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## NEDSS and the Environmental Health Tracking Network (EHTN)

- NEDSS can provide in coordinated fashion with investments made for IT capacity for emergency preparedness, the necessary infrastructure upon which the EHTN can be built.
- NEDSS has defined data types useful for public health as well as standard codes, vocabularies and messages to describe and electronically transmit those data; additional resources/work needed to define data standards for environmental exposures



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## Third National NEDSS Stakeholders' Meeting

- May 10 & 11, 2002; ~ 600 participants
- Broad representation from states, local health departments, public health laboratories, and private clinical care, partner organizations, CDC, HRSA, CMS
- Active exchange of information on NEDSS implementation, including demonstration of Base System
- Strong interest in how NEDSS standards based approach and infra-structure could be used to support broader health department information needs, for example web based Vital Statistics systems, HIPAA



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**Office of Integrated Health  
Information Systems**

- Claire Broome, MD – Senior Advisor to Director (cvb1@cdc.gov)
- Mike Donnelly – Deputy (mrd1@cdc.gov)
  
- (404) 639-7860
- [www.cdc.gov/nedss](http://www.cdc.gov/nedss)



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