

Georgia

Project title: Georgia Newborn Surveillance and Tracking Information Integration Project

Organization responsible: Maternal and Child Health Section (MCH), Epidemiology Branch, Georgia Division of Public Health, Department of Human Resources

Service coverage area: State of Georgia

Annual birth cohort: Approximately 137,000

Project scope and goals

The ultimate goal of the Georgia Newborn Surveillance and Tracking Information Integration Project is to develop a consolidated Web-based newborn surveillance and tracking system (NSTS) for the collection, management, and analysis of newborn and child health and case management information with secure access by a range of approved private and public health care providers, and district, local, and state-level program managers and epidemiologists.

NSTS is envisioned as a backbone for Children 1st, Universal Newborn Hearing, Screening and Intervention, Georgia Childhood Lead Poisoning and Prevention Program, Georgia Birth Defects Reporting and Information System, the Genetics Services Program, and potentially other special needs child health programs to provide and access information regarding the health status of each child receiving public health services.

The project focuses on:

- Securing and deploying the information infrastructure to integrate child health information from specified relevant data sources.
- Ensuring screening, diagnosis, and interventions by tracking individual infants and children.
- Describing and monitoring the incidence of hearing loss, birth defects, blood lead levels, genetic and metabolic conditions in infants and children through surveillance.

Specific project objectives are directed toward developing a population-based newborn surveillance and tracking system by integrating health information across newborn screening information systems, including birth registration, metabolic, and hearing screening.

Funding

CDC EHDI grant, HRSA Genetics Services grant, HRSA EHDI grant, SSDI funds, state funds.

History

In September 2000, the Division of Public Health was awarded the Early Hearing Detection and Intervention (EHDI) grant through the Centers for Disease Control and Prevention (CDC) to fund development and implementation of an EHDI data tracking and surveillance system. The EHDI grant has been used in part to plan the development of a Web-based integrated Newborn Surveillance and Tracking System (NSTS) to allow for complete tracking and surveillance of children to age five. NSTS is proposed to support Children 1st (Georgia's equivalent of a Child Find program), the Universal Newborn Hearing Screening and Intervention program (UNHSI), the Georgia Birth Defects Reporting and Information System (GBDRIS), and the Georgia Lead Poisoning and Prevention Program (GLPPP).

A primary goal of the NSTS project is to create a screening profile of each newborn and a health profile of each child receiving public health services, accessible by service providers. This point-of-service access should decrease the need for redundant treatment or services as children move across districts and health care providers. Key project objectives include integrating metabolic screening data and electronic birth data with NSTS to create a population-based system; improving compliance with notifiable disease and Children 1st reporting requirements; ensuring referral to and the provision of follow-up services for children identified with socio-economic and medical risk factors; and monitoring children with hearing impairment, birth defects, and other conditions from identification to discharge from the Children 1st program.

In 2003, MCH was awarded a four-year HRSA Genetics Services grant to support integration of child health information. This HRSA grant supports the Vital Records Branch (VRB) procurement of a Web-based birth and fetal death registry that will be integrated with NSTS through the Office of Information Technology (OIT) and the Georgia Technology Authority (GTA) information technology infrastructure. VRB began the development of the Web-based Vital Events Information System (VEIS) in April, 2005.

MCH initiated the process to procure the proposed Web-based integrated NSTS in 2003. MCH explained the need for, purpose, and anticipated impact of NSTS to the State Advisory Committee for Newborn Hearing Screening and the largest birthing hospitals and regional perinatal centers and garnered their support. From 2003 through 2004, MCH worked closely with the OIT, the VRB, Children 1st, UNHSI, and Genetics Services programs, the GBDRIS and the GLPPP to define and establish the NSTS business and technical requirements. In 2004, use-case modeling depicting current work processes and information flow for the five functional components of NSTS was completed.

MCH and OIT established a five-year timeline for the development and implementation of a solution that is architected to provide functionality for birth defects surveillance and tracking, genetic, and metabolic screening and follow-up, newborn hearing screening, tracking and surveillance, blood-lead

surveillance and the Children 1st program and to support the following levels of integration:

- 1) Newborn screening results;
- 2) Birth and fetal death records from the planned web-based electronic birth registration system
- 3) Automated hospital hearing screening test results
- 4) Laboratory reports of blood lead test results
- 5) Electronic birth defect records abstracted from hospital medical records.

Anticipated users of NSTS include: hospitals (nursery, audiology, NICU and medical records staff), private providers (pediatricians, geneticists, audiologists, and family practitioners), district and county public health staff (including Children 1st, UNHSI, Regional Lead Coordinators, public health nurses, and possibly Children with Special Needs staff), state level epidemiologists, and program managers.

With the collaboration of OIT and GTA, MCH developed a request for proposals to develop and implement the integrated Web-based NSTS solution. DPH released the request for proposals to procure a vendor for NSTS in December 2004. The contract was awarded in April 2005. The vendor began the first phase of the project in May 2005.

Executive leadership and organizational endorsements

The Director of the Division of Public Health and the Branch Chiefs of both the Family Health Branch and the Epidemiology Branch strongly support the NSTS initiative. The Public Health Liaison to OIT reports directly to the Director of the Division and provides guidance to OIT on all public health information system projects. He has prioritized both the Vital Events Reengineering Project (VEIS) and NSTS projects. MCH works collaboratively with OIT and GTA toward procuring and implementing both NSTS and VEIS. The Vital Records Branch is also a key partner in this initiative.

External endorsements

The following organizations and committees fully endorse the development of a statewide web-based integrated child health information system:

- Georgia PINES
- State Advisory Committee for Newborn Hearing Screening
- Northside Hospital
- State Newborn Screening Advisory Committee

Significant challenges

- 1) A significant delay was created by the reorganization of DHR/OIT and the implementation of new procedures requiring several months of additional review and revisions to the RFP. Furthermore, the conceptual plan for the public health information infrastructure was in flux until recently. Therefore, technical aspects of the RFP were incomplete pending final technical input

from OIT. In addition, new procedures were implemented by GTA for processing RFPs and the NSTS RFP became a test case for the new processes. These new OIT and GTA procedures cost the project more than six months of additional review.

- 2) Developing, testing, and deploying de-duplication and matching processes for electronic birth, newborn screening, and newborn hearing records.

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