

Colorado

Project title: Newborn Evaluation, Screening, and Tracking (NEST)

Organization responsible: Colorado Department of Public Health and Environment, Children and Youth with Special Health Care Needs Section

Service coverage area: State of Colorado

Annual birth cohort: Approximately 70,000

Project scope and goals

The Newborn Evaluation, Screening, and Tracking (NEST) project is creating a Web-based system that can link the statewide blood spot screening database with a statewide hospital-based hearing screening database pre-populated with demographic information from the state's electronic birth certificate registry. This is regulated by a central function that uses XML to move data in and out of the system. The business rules that control this information sharing – and the hierarchy of rights for viewing the information – are programmed in Microsoft BizTalk 2004. The team is presently testing this central function and its ability to de-duplicate data from different sources. They are also testing how data moves from clinical partners through the central facility and on to public health nurses in the field, as well as the nurses' ability to communicate back to the state health department. This function will be used to report on the status of the medical home for children with special health care needs identified initially by newborn screening.

The project team is also creating a link to the developing immunization registry with the goal of eventually allowing medical providers to engage in the central function. This will allow providers access to newborn screening results (with parental permission) and the ability to check the immunization registry in real time at the point of service. The health department is also linking to a birth defects registry. Future plans include integration with a child traumatic brain injury database, and the next iteration of the EHDI grant plans to link to Colorado's Part C database for Children with Special Needs.

Funding

CDC EHDI grant, MCHB Genetics State Health Information Systems Integration grant, and MCHB SSDI grant.

History

This project began as an idea at an MCHB meeting hosting states that were embarking on state genetics planning grants. With the opportunity to apply for level II funding (included newborn metabolic and hearing screening database integrations) for CDC EHDI grants, these nascent ideas became a reality. MCHB

Genetics State Health Information Systems Integration grant and SSDI supplemented the process partially and sequentially.

Executive leadership and organizational endorsements

Chief Medical Officer, Title V, Vital Records, and Information Technology at the state health department level.

External endorsements

University of Colorado Health Sciences Center labs and clinical services related to genetic conditions, Part C of IDEA, March of Dimes.

Significant challenges

- 1) Hiring computer programmer expertise that is appropriate to cutting edge technology applications. The state personnel system is not well adapted to these hiring needs.
- 2) Difficulties in working with internal partners who are not ready to participate in this collaboration. There has also been an issue in setting up what may be a surveillance system. This may threaten some with loss of perceived control of public health research endeavors.

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