

Washington

Project title: Maternal and Child Health Data Integration

Organization responsible: Washington State Department of Health, Genetic Services Section

Service coverage area: State of Washington

Annual birth cohort: Approximately 80,000

Project scope and goals

Initial efforts of the integration project focused on physically linking the state's newborn metabolic screening follow-up program with the newly developed Early Hearing loss Detection, Diagnosis, and Intervention (EHDDI) program. This project was completed and has proven very successful.

Project staff are now exploring the feasibility and costs associated with linking the newborn screening data sets with additional data sets managed by the State Department of Health, including vital statistics, the Children's Health, Immunization, Linkages and Development Profile (an immunization registry known as the CHILD Profile), and the birth defects surveillance system. This analysis will include identification of technical barriers as well as legal or policy barriers – and approaches to overcome those barriers.

Funding

- CDC: Early Hearing loss Detection, Diagnosis, and Intervention (EHDDI) grant
- HRSA: State Genetics Plan Implementation grant

History

Washington began developing the surveillance and tracking system for EHDDI in 2000, and staff quickly realized that the system had significant overlaps in process and data elements used in the tracking and surveillance of newborns for metabolic conditions. For this reason, a feasibility study was conducted to determine the most advantageous way to create the EHDDI system while taking advantage of processes already in place for follow-up of newborns with metabolic disorders. The system was completed in 2003 and piloted with six birthing hospitals for a year before adding all other birthing hospitals in the state (N=68).

Once this system was completed and demonstrated its efficiency, staff began to explore further integration efforts. In 2005, the team will begin linking varied data sets, including vital statistics and CHILD Profile, while simultaneously understanding possible technical or legal barriers.

Executive leadership and organizational endorsements

With staff support from the Division of Resource Management, a group of mid-level managers is leading the project.

External endorsements

The Washington State Hospital Association, numerous birthing hospitals, and the State Board of Health have commended the NBS/EHDDI system as necessary and successful. Maternal and Child Health stakeholders have expressed approval of further integration efforts. The project team has not requested external stakeholders to provide formal endorsements.

Significant challenges

- 1) *Funding*: Given limited resources, it is difficult to ensure that integrated systems can be sustained and maintained long-term.
- 2) *Leadership*: Acquiring senior management support for integration projects requires extra effort and perseverance.
- 3) *Access*: Striking a balance between protecting confidential information and allowing access to providers who may be better able to serve clients by having access to the information poses challenges.

Contacts

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