

**Project Title:** Improving Quality Care for Children with Special Needs  
**Principal Investigator:** Lozzio, Carmen B, M.D., F.A.C.M.G.  
**Organization:** University of Tennessee, Knoxville  
**Mechanism:** RFA: HS05-013: Limited Competition for AHRQ Transforming Health Care Quality through Information Technology (THQIT)  
**Grant Number:** UC1 HS 016133  
**Project Period:** 09/05 – 09/09, Including No-Cost Extension  
**AHRQ Funding Amount:** \$1,096,491  
**Summary Status as of:** December 2008

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**Strategic Goal:** Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

**Business Goal:** Knowledge Creation

**Summary:** This 4-year project focuses on using health information technology (IT) to improve quality of care to children with special health care needs (CSHCN). The researchers are developing a secure, Web-based electronic health record (EHR) called the Tennessee Child Health Profile (TN-CHP) that will provide comprehensive information on CSHCN after parental approval. The TN-CHP will be designed to link the data on newborn screening (NBS) and newborn hearing screening (NHS) from the public health database of the Tennessee Department of Health with data on diagnosis, treatment, and follow-up from programs providing services to CSHCN. Outcome measures for follow-up of NBS and NHS and tracking of diagnosis, including follow-up services for CSHCN, will be analyzed. The lag time will be investigated by birth weight of the babies tracked over time from date of birth. TN-CHP will help the primary care providers and parents or legal guardians access and manage CSHCN information more easily, which will make primary diagnosis more efficient.

### Specific Aims

- Make the TN-CHP available to providers and parents/legal guardians. **(Ongoing)**
- Develop an integrated TN-CHP for CSHCN. **(Ongoing)**
- Perform statistical analysis of data to measure outcomes. **(Ongoing)**
- Improve the safety and quality of care of CSHCN. **(Ongoing)**

**2008 Activities:** In 2008, the researchers continued to develop the EHR, TN-CHP for CSHCN. There were extensive meetings and conference calls with the six key providers of services to CSHCN, the Tennessee Department of Health, and the Vanderbilt Center for Better Health. The Web browser and the TN-CHP demo were also developed. There was progress in the statistical analysis of data to measure outcomes. An informational brochure on this project was produced and distributed to the providers and parents. Institutional Review Board (IRB) approval was received for the project, and patient recruitment began.

**Preliminary Impact and Findings:** The goals and specific aims of this project and the development of the TN-CHP as an EHR that summarizes complex medical and developmental information on CSHCN have been received with enthusiasm by providers of specialized care for children with genetic disorders and developmental disabilities. It is expected that the use of TN-CHP by pediatricians and other providers of ambulatory care will improve the coordination of services and quality of care provided to these children.

The preliminary outcome measures imply that the birth weight is an important factor in the length of time required to report abnormal results in premature infants.

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### **Selected Outputs**

The principal investigator participated in the AHRQ 2008 Annual Conference for “Promoting Quality...Partnering for Change.” September 2008, Bethesda, MD.

Researchers collaborated with the Tennessee Department of Health, Vanderbilt Center for Better Health, and the MidSouth eHealth Alliance to improve coordination of services and quality of care for CSHCN.

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**Grantee’s Most Recent Self-Reported Quarterly Status:** During the last reporting quarter in 2008, researchers explored the possibility of linking the TN-CHP to the Tennessee Information Infrastructure (TNII) connectivity system. The NBS Web site was improved to make access easier to providers, and the educational section is also being improved and updated. Access to NBS results was improved by using relevant identifiers. Progress was made in analyzing the lag times between birth, first collection, and repeat screening for the NBS tests performed by the State laboratory in children born in Tennessee during 2007 and 2008. The budget was managed during the third year of funding (9/2007–8/2008), to accommodate continued activity in the project’s no-cost extension year (9/2008–9/2009).

**Milestones:** Progress is mostly on track.

**Budget:** Somewhat under spent, approximately 5 to 20 percent.