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Principal Investigator:

Carmen B. Lozzio, MD, FACMG

Team members:

David Hollar, PhD

Rosalyn Lemak, MPH

Robert Eubanks, MS

Lee Fleshod, PhD

John Phillips III, MD *

Jewell Ward, MD, PhD †

Frederick B. Palmer, MD ‡

Robin Mc William, PhD §

* Vanderbilt Genetic Center

† Genetic Center at UT Memphis

‡ Boling Center for Developmental Disabilities, UT Memphis

§ Center for Child Development, Vanderbilt University

Performing Organization:

University of Tennessee, Health Science Center, Graduate School of Medicine, Department of Medical Genetics

Project Officer:

Iris Mabry, MD

Submitted to:

The Agency for Healthcare Research and Quality (AHRQ)

U.S. Department of Health and Human Services

540 Gaither Road

Rockville, MD 20850

www.ahrq.gov

Abstract

Purpose: To develop the Health Information Technology (HIT) infrastructure in Tennessee to promote and improve the safety and quality of health care for children with special health care needs (CSHCN).

Scope: To expand an electronic health record linking data from newborn screening (NBS) newborn hearing screening (NHS) and birth certificates to include other CSHCN. The planning project focused on integration/linkage of data for the Tennessee Child Health Profile (TN-CHP), with implementation of web browser data access to case managers and primary care physicians (with parental permission).

Methods: The partners are the Genetic Centers at UT Knoxville, UT Memphis and Vanderbilt, the Child Development Center at Vanderbilt, the UT Boling Center for Developmental Disabilities in Memphis and an acute care hospital (University Health Systems /UT Medical Center). The users include rural and urban providers. TN-CHP will include data on each child linked via a secure data warehouse located at UHS on the same Local Area Network (LAN) as the web server, and both will be behind Cisco firewalls. Once consent has been given by the parent /guardian the child's health data will be imported from the partner's sites into TN-CHP by Virtual Private Network (VPN).

Results: Major successes include: 1) Participation of major stakeholders; 2) arrangements for data sharing between the partner organizations; 3) IRB approval from UT and TDH; 4) involvement of Physicians; and 5) collaboration with the Vanderbilt Volunteer e-Health Initiative, a major AHRQ funded RHIO project.

Key Words: e-health record; children with special needs; data linkage

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Final Report

Purpose

The purpose of this project is to develop the Health Information Technology (HIT) infrastructure in Tennessee to promote and improve the safety and quality of health care for Children with Special Health Care Needs (CSHCN). An electronic health record called Tennessee Child Health Profile (TN-CHP) is being developed for infants with disorders detected by the state Newborn Screening (NBS) and Newborn Hearing Screening (NHS) programs and for children with other genetic disorders and developmental disabilities diagnosed at the major Genetic and Child Development Centers in the state. The use of this electronic health record (TN-CHP) by pediatricians and case managers will improve the quality of follow up and management services for CSHCN.

The project GOALS include to:

1. Develop the Health Information Technology (HIT) infrastructure in Tennessee to promote and improve the safety and quality of health care for Children with Special Health Care Needs (CSHCN).
2. Promote cooperative agreements between providers of health care for CSHCN and linkages of databases developed by each provider.
3. Make available to health care providers the access to an integrated electronic health record of CSHCN (with parental permission) through a secure web based system.

The specific aims for these goals are to:

- 1.1. Develop a comprehensive Child Health Profile for CSHCN based on the same principles of the Child Health Profile developed for infants identified by State Newborn Screening (NBS) and Newborn Hearing Screening (NHS) programs.
- 1.2. Improve the coordination of services, timelines of follow-up services, and patient tracking to avoid loss of cases that need services and reduce delays in delivering appropriate treatments.
- 1.3. Improve information on the primary diagnosis for children seen by different specialists.
- 2.1. Incorporate into a common web based browser the data from the databases for CSHCN and for NBS/NHS and include the databases developed by various state departments such as Tennessee Early Intervention Services (TEIS) from the TN Department of Education, Children's Special Services (CSS) from the Tennessee Department of Health (TDH), and EPSDT data from the Bureau of TennCare (i.e., State Medicaid).

2.2. Integrate systems of early identification with early intervention services.

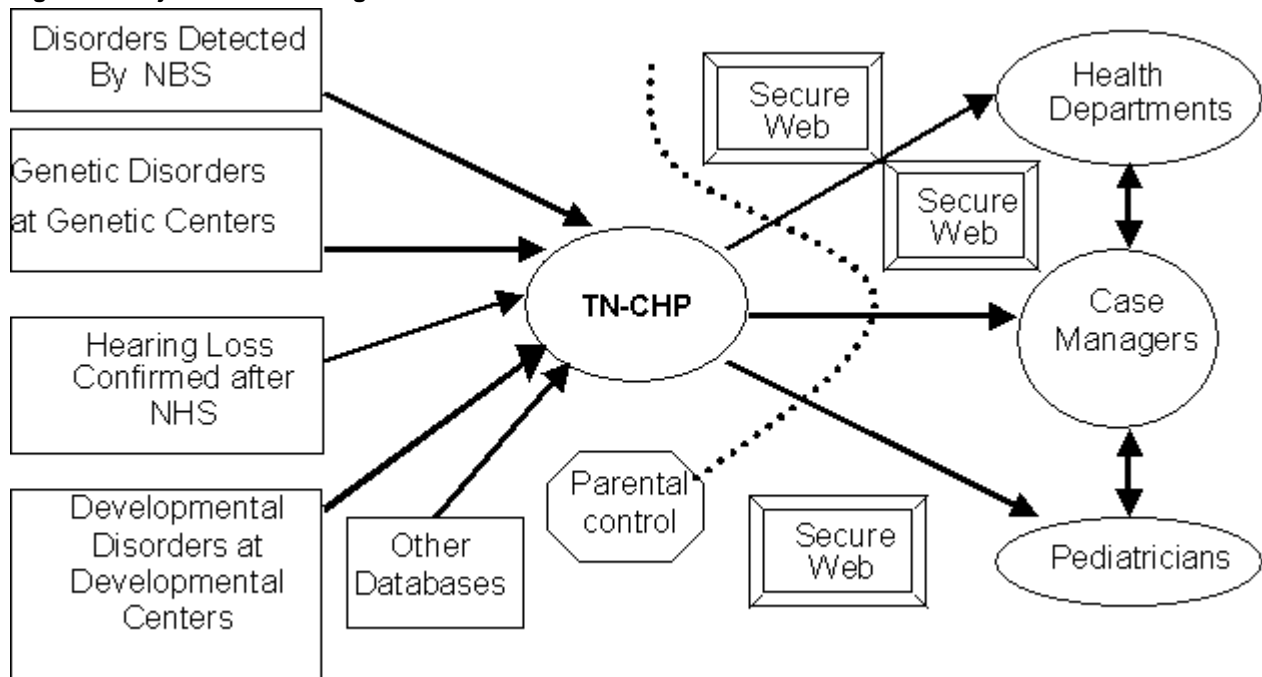
2.3. Increase communication between all aspects of the health care and educational systems to improve the quality of life of CSHCN.

3.1. Offer to health care providers all relevant health information on a child (with parental permission) from a single secure web source, thus freeing the provider from searching through multiple web sites, electronic records, and manual files to obtain information.

3.2 Give parents access to their child's records and an electronic mechanism to communicate their concerns, record the progress made and other relevant information.

Based upon these goals and the corresponding aims, this project proposed to develop an electronic health information system for children with special health care needs (e.g., genetic and metabolic disorders, birth defects, developmental disabilities). The electronic record is called Tennessee Child Health Profile (TN-CHP). During the planning process, agreements were established with the TDH to integrate the database for infants with disorders screened by the state NBS and NHS programs with other databases. Integration of TN-CHP to additional databases such as Children's Special Services (CSS), Tennessee Early Intervention Services (TEIS), Women Infants and Children (WIC) and TennCare EPSDT data will be a major goal of the implementation phase of this project. The web based EMR called TN-CHP will be accessed by case managers and pediatricians (with parental permission). Additionally, partnerships will be developed between the project applicants and providers of long-term health and educational case management services for this population. Figure 1 shows a vision of this project.

Figure 1. Project database long-term vision



Scope

Background

Approximately 13 percent of all American children have a special health care need (CSHCN; 1-3). During 2004 in Tennessee, there were 80,976 births. Estimates are that as many as 10,000 children born each year in Tennessee may be diagnosed with a disability during their childhood (4). Research indicates that many CSHCN receive inadequate follow-up care (3, 5-9). Rhode Island's KIDSNET electronic child health profile (ECHP) has demonstrated its utility in addressing these problems (10-13).

Many CSHCN are disproportionately poor, socially disadvantaged, and face significant barriers to health care (17, p. 117). Nearly 18% have an unmet need for specific care services (1, 6), 11% had no personal care provider (1, 8), and nearly 22% encountered difficulty receiving referrals for specialty care (1, 6). Most of CSHCN who lived in the South or West had increased limitations, low socioeconomic status and they were significantly more likely to have experienced delayed or forgone care (3). Financial problems, and time conflicts were among the major factors associated with delayed or forgone health care for CSHCN (3). Besides being more likely to not receive appropriate care, CSHCN and their families are less likely to receive effective health education, and there are few standardized quality measures for assessing children's health care (22-23).

Since 2001, the United States Department of Health and Human Services (DHHS) Health Resources and Services Administration (HRSA) has awarded 22 state planning grants, 11 state implementation grants, and five joint program initiative grants under the Title V Maternal and Child Health SPRANS Genetics Services program (39-40). This program was initiated in response to the American Academy of Pediatrics Newborn Screening Task Force (48) report, which recommended expansion of newborn screening programs and database integration in accordance with the Institute of Medicine's (49) report outlining the three core functions for public health agencies: (a) policy development, (b) assurance, and (c) assessment. The AAP Newborn Screening Task Force (43) also stressed the role of emerging technologies and the development of the public health data infrastructure in improving child health services.

The DHHS Agency for Healthcare Research and Quality (AHRQ) has funded medical organizations in the development of improved data quality mechanisms since 1968. Since then, substantial AHRQ attention has been provided to clinical laboratory automation, improvements in health information technology, and health data coding and standards (21, 30, 43-44). Within institution data linkages with coding and messaging standards as well as automation of systems communications has been achieved at the Regenrief Institute for Health Care in Indiana (44-47).

As part of these efforts, the Department of Medical Genetics at the University of Tennessee Graduate School of Medicine in Knoxville was awarded a four-year, joint program initiative grant from HRSA in 2003 and a one year Health Information Technology Planning grant from AHRQ in 2004. The collective purpose of these two projects is to integrate the Newborn Genetic Screening (NBS) Program and other genetic services into the Information Technology (IT) plan to assure an adequate public health infrastructure and to coordinate genetic services with all other programs for children with special health care needs (CSHCN). This purpose includes the strategic goal of (a) developing an electronic child health profile that links data from Newborn Genetic/Metabolic Screening, Hearing Screening, Birth Certificate, and Vital Records for all

children born in Tennessee and (b) making this information available in a secure, accessible format for providers, with appropriate parental/guardian permissions.

Context: Health Information Technology

There is a growing consensus among public health practitioners that information technology represents an essential but underused tool for improving health care (24-27). Linked information systems have been widely utilized in business, but not in health, with the exception of patient billing records. Immunization registries have been in the forefront of health care database development and serve as the model systems for linked public health databases to produce electronic medical records (28). The use of pediatric electronic medical records can (a) facilitate information sharing among providers, families, and other key health stakeholders, (b) empower children and families, (c) improve healthcare system efficiency, (d) optimize access to services for CSHCN, (e) reduce redundancies, medical errors, and record unreliability, (f) enable long-term tracking of migration, morbidity, and mortality, (g) reduce medical and healthcare costs (29-34), and (h) improve continuity of care. A central principle in these efforts is that “data are for sharing” (26, 28, 31-32, 35).

A pre-post intervention comparison of paper versus electronic medical records access among pediatricians (36) demonstrated significant differences in the documentation of physical examinations, developmental milestones, immunization updates, and risk assessment parameters, all of which improved with the utilization of electronic data sources. Utilization of data linkages between immunization, WIC, and other databases in Michigan improved the percentage of infants age 19-35 months who were up-to-date on their immunization schedules from 42% in 1991 to 81.6% in 2002 (37).

The Rhode Island Department of Health’s KIDSNET electronic health record has been at the forefront of state efforts to link health records for all of the approximately 13,000 children born in that state each year. By 2003, Rhode Island had linked pediatric electronic health records on 84,000 children born since 1997 for the following datasets: (a) Newborn developmental risk, (b) Newborn genetic and metabolic screening, (c) Newborn hearing screening, (d) Immunization records, (e) Childhood lead poisoning, and (f) Vital records (10-13). Additionally, the KIDSNET program has a family-centered focus, is targeting additional databases (e.g., WIC, Early Intervention, Family Outreach, and Birth Defects), generates automatic reminders and mailers, has 70% of its children immunized, and reaches 50% of primary care providers in the state (11-13). The project also utilizes an extensive, well-organized statewide network of key medical, health, consumer, advocacy, and legislative stakeholders.

State linked public health data systems such as Rhode Island’s KIDSNET have evolved along several overlapping and complementary trajectories, including (a) the National Electronic Disease Surveillance System (NEDSS), (b) Robert Wood Johnson Foundation funding of All Kids Count and Connections Community of Practice (28, 38) programs to provide 40 planning and implementation grants for state immunization registries (1992-2000) and further linkages to develop integrated child health profiles (2000-2004), (c) Health Resources and Services Administration (HRSA) planning and implementation grants to integrate newborn screening programs with other child health data systems (39-40), and (d) Agency for Healthcare Research and Quality Information Technology and Implementation grants to improve the efficiency of healthcare delivery in the United States.

The NEDSS initiative (41) involves the integration of various information systems on a statewide level using HL7 messaging and is oriented towards specific health conditions (e.g., state surveillance systems for vaccine preventable diseases utilizing immunization registries). As of October, 2003, two states (Nebraska and South Carolina) had PHIN-compliant NEDSS programs in use, and six states (Alabama, Indiana, Louisiana, Tennessee, Texas, Virginia) were deploying NEDSS programs, out of 29 participating states (42).

All Kids Count programs have emphasized the integration of immunizations, newborn screening (NBS), early hearing detection and intervention (EHDI) and vital registration records as primary goals because these assessments are mandated in most states, followed by the integration of WIC, lead screening, Medicaid/EPSTD, birth defects surveillance, and other databases as secondary goals (28). These programs complement the HRSA-funded programs in Maternal and Child Health and the AHRQ programs to improve quality of medical care.

Settings: Demographics

The population of Tennessee has increased significantly in the 1990s compared to the 1980s. It was estimated at 5.3 millions in 1995 and 5.7 millions in the year 2000. This increase ranked Tennessee as having the ninth largest in the nation. The projection by the year 2025 is 6.7 million people.

Past distribution of Tennessee's population was 17% black, 82% white and 1% other races. However, Tennessee is expected to gain 97,000 people through international migration between 1995 and 2025 and expected to gain 845,000 people through internal migration for the same time period. All ethnic and racial groups are expected to increase during this time period except for non-Hispanic whites. African-Americans, Asians, and persons of Hispanic origin will experience the greatest gain. Hispanics are the largest ethnic minority in Tennessee. The 1998 Bureau of Census population estimates, 62,223 persons, or 1.1% of all Tennesseans, identified themselves as being of Hispanic origin. The Hispanic population is most likely larger than the reported number due to the growing population of migrant workers and undocumented residents across the state. According to the 2000 Census, the Hispanic/Latino population in Tennessee was 123,838 representing 2.2% of the state's population, twice the number estimated in 1998 by the Census Bureau.

Tennessee has a wide variety of ethnic groups in addition to Hispanics. Southeast Asians are the second largest group (52,564), and the state is fifth largest Kurdish resettlement site in the nation. Refugees and legal immigrants are now arriving from African, Baltic, Central Asian and Southeast Asian countries. Nashville, Tennessee has the largest Kurdish population in the nation estimated at 5,000 persons and settlements of refugees from Iraq, Somalia, and Sudan. The state anticipates refugees especially women and children from Afghanistan, Sudan, Burma, and Sierra Leone. These refugees are from war torn countries where rape and torture were commonplace. They are expected to have significant health problems. Current ethno-cultural barriers include language, educational level, health care customs, and religious restriction against medical intervention. Over 30 different languages are spoken as the primary language of the home in metro-Nashville. Each major medical institution in the state has a network of locally available interpreters, and, statewide, the Tennessee Foreign Language Institute maintains a database of translators and interpreters for a wide range of linguistic needs. Other resources are available in more isolated communities, including the AT&T Language Line, which can be subscribed to (1-800-643-2255). Educational level and health care customs are sometimes

barriers. Most medical institutions have found that parents are not resistant to treatment and therapy when the issues are appropriately explained. Religious prohibitions are also rare, but Tennessee law is clear on the obligation of caregivers to bring to the attention of the TDCS any instances in which denied treatment would result in harm to the child.

East Tennessee has 35 counties and contains the Appalachian Mountains at its eastern boundary and the Cumberland Mountains at its boundary to the west. The population of the region is 92% Caucasian, 6% African-American, and 2% of other races. Some of the counties of East Tennessee (Cocke, Loudon, Hamblen, and Unicoi) have a larger percentage of Hispanics due to an influx of migrant workers about 3 to 5% of the total population. East Tennessee has a larger percentage of children born with some autosomal recessive disorders such as PKU and galactosemia. Other congenital anomalies such as neural tube defects (spina bifida, myelomeningocephaly, and anencephaly) also have an increased incidence in this area. The frequency of familial mental retardation is also high and large families with inherited disorders such as fragile X mental retardation has been observed in this area.

Middle Tennessee has 39 counties and is part of the plateau of the Cumberland Mountains and flat fertile rural areas. The population is 86% Caucasian, 12% African-American, and 2% all other races. This region had the largest increase in population growth between 1990 and 1995 with an average increase of 11%. The Nashville area has the largest concentration of immigrants and refugees (50-60%) of the entire state. This region of the state has a high percentage of the population that has moved to the state from other areas of the country.

West Tennessee has 21 counties and the largest percentage of sickle cell disease in the state and 75% of the cases with this disorders are born in this region. The rural areas are sparsely populated with the largest population residing in the city of Memphis, population of over 600,000. The population of this region includes 63% Caucasians, 35% African-Americans, and other races making up the remaining 2%.

In summary, the diversity of races, cultures, and the presence of rural and metropolitan areas within each of the three grand divisions of the State represent a challenge and an opportunity to compare strategies that may be useful for the integration of services with a family centered, community based approach.

Participants

The AHRQ Planning grant and the currently awarded Implementation grant includes the following providers of healthcare services to children with special healthcare needs:

- A) **UT Graduate School of Medicine.** The Graduate School of Medicine is part of the University of Tennessee Medical Center. The GSM consists of 170 residents and 200 faculty members in 11 residency programs, including Anesthesiology, Family Medicine, Obstetrics and Gynecology, Pathology, Pediatrics, Radiology, Surgery, Oral/Maxillofacial Surgery, and Medical Genetics.

The UT Genetic Center/Department of Medical Genetics. The Department of Medical Genetics at UT Graduate School of Medicine houses the Genetic Center, one of the three Genetic/Metabolic Centers in the partnership. A detailed description is available at www.utmedicalcenter.org/genetics and the following is a brief summary: Clinical Genetic Services are provided for children and families and are scheduled at the Center

and at Outreach Genetic Clinics located at public health departments and local pediatrician's offices in ten counties of East Tennessee. In-patient consultations are available as needed (24hrs/7days/all year) at UT Medical Center and area hospitals. These services include general genetics, prenatal counseling, risk counseling for breast cancer and other hereditary cancers. Diagnosis, treatment and follow-up services are provided to infants with metabolic disorders such as PKU and Galactosemia, identified through the State Newborn Screening program. Outreach Clinics are located in Huntsville; Kingston; LaFollette; Loudon; Madisonville; Morristown; New Tazewell; Newport; Oak Ridge; Sevierville. The Center has three specialized laboratories: Clinical Cytogenetic and Molecular Cytogenetic Laboratory; Biochemical Genetics Laboratory and Molecular Genetics Testing Laboratory.

B) The UT Medical Center/University Health Systems. This acute care hospital is recognized for its pioneering efforts in science and technology and is committed to staying on the forefront both regionally and nationally. Recent developments include a) clinical trials on the first 16-slice PET/CT by the UT Cancer Imaging and Tracer Development Program, b) two new Bell 430 helicopters were acquired for the LIFESTAR emergency transport services and a second air ambulance base was established at Morristown-Hamblen Hospital with GPS capabilities for increased response times to rural counties in East Tennessee, Kentucky, and North Carolina, c) UHS reached an agreement with Accuracy, Inc. of Sunnyvale, California to place a frameless stereo tactic surgery system at UT Medical Center, d) the UT Neonatal Transport Team became one of only two neonatal units in the world to install and use the new Bronchotran I Ventilator, a high frequency and versatile ventilator for air and ground transports, e) UHS implemented with CyraCom International, Inc. a new foreign language interpretation system to optimize physician-client communication and education, f) a new patient placement center was established to assist in a clinical review of patient needs upon referral to the hospital, and g) a partnership with CareScience, Inc. was established to enhance case management and performance improvement efforts.

The UHS Department of Information Services, directed by Mr. Buddy Fain, provides systems that support the UHS strategic goals and objectives by enabling coordinated, efficient, and effective access to clinical information throughout the continuum of care. The department partners with customers to design and deploy information technology that presents reliable, timely, accurate, and integrated information to improve decision-making focused on quality care and customer service. Network infrastructure resources include Electronic Medical Record accessible by patient and provider, Physician Order Entry, Optimized Access to the Healthcare Delivery Team, the protection of Data Integrity and Confidentiality, Patient Safety, Process Improvement, and the measurement of clinical outcomes (for more information see www.utmedicalcenter.org).

C) The Genetic Center, Division of Medical Genetics (Department of Pediatrics) Vanderbilt University School of Medicine. The Division of Medical Genetics, directed by John A. Phillips, III, MD, FACMG, is one of three Genetic/Metabolic Centers in the partnership. General genetic clinics are available at Vanderbilt University Medical Center (VUMC) and in outreach clinics at public health departments in Middle Tennessee. In-patient consultations are available 24 hours a day, 7 days a week at Vanderbilt Hospital

and at area hospitals upon request. Specialty genetic services at VUMC include metabolic, prenatal, hemostasis-thrombosis, cystic fibrosis, Down syndrome, familial cancer and predictive testing [for neurological conditions including Huntington disease and hereditary ataxias and familial primary pulmonary hypertension (FPPH)] clinics. Enzyme replacement therapy is provided for a variety of metabolic conditions including Gaucher, Fabry, MPS 1 and 1-S through the Lysosomal Storage Disease Center. Prenatal and specialty counseling is also provided two days per week at Baptist Hospital and at outreach clinics. Outreach clinics are located in Columbia; Cookeville, and Clarksville.

The center has the following genetic laboratory services: Biochemical testing and Molecular Diagnostics Research currently being conducted in the Division of Medical Genetics (Department of Pediatrics) involves collaborators within the Vanderbilt community, the United States (academic and private industry) and the international community. Areas of focus include causes and treatment of collagen disorders such as spondyloepiphyseal dysplasia tarda, and urea cycle disorders, the molecular genetics of nitric oxide metabolism, glutathione and growth hormone deficiency, hemochromatosis, angioedema, autism, mitochondrial disease, multiple lipoma, carotid artery tumor and multiple keloid syndromes, dyslexia, familial obesity, persistent pulmonary hypertension of the newborn and following cardiac surgery, PPH and idiopathic pulmonary fibrosis and genetic counseling issues in predictive testing for complex diseases. In addition, the Medical Genetics Division has taken a leadership role in the Vanderbilt Clinical Research Center Genetic Initiative.

D) The Genetic Center at the University of Tennessee Center for Health Sciences, Memphis, Department of Pediatrics, Division of Medical Genetics. This is one of the three Genetic/Metabolic Centers in the partnership. The division is directed by Jewell C. Ward, MD, PhD and has three full-time ABMG Certified Clinical Geneticists (Dr. R. Wilroy and Dr. E. Pivnick, in addition to Dr. Ward); they hold 8 General Genetics Clinics per month. Specialty Genetic Clinics include Inborn Errors of Metabolism Clinics (2/month) and a Genetic Neurofibromatosis Clinics (2/mon). Outreach General Clinics (2 /month). Clinical Geneticists provide immediate genetic evaluations to 7 birthing hospitals in Shelby, and are on the consulting staff of an additional 2 hospitals. Services include diagnostic genetic evaluations of individuals with dysmorphism, genetic counseling for at risk family situations (multiple fetal wastage, family history of genetic disorders, reproductive risks due to exposures) and presymptomatic genetic evaluations. The division has affiliation with the Department of OB/GYN, ABMG Certified Reproductive Clinical Geneticist, who holds weekly prenatal diagnostic services, including advanced ultrasonography, amniocentesis and CVS procedures. The center provides services to citizens in over 25 counties in W. Tennessee, as well as citizens in E. Arkansas, N. Mississippi, N. Alabama, and S. Missouri. This Center, in conjunction with the U.T. Boling Center for Developmental Disabilities, has provided follow-up diagnostic and nutritional treatment services for the designated W. Tennessee catchment area for presumed positives of hyperphenylalaninemia and galactosemia. The U.T. Boling Center Metabolic Nutritionists provide specialized services to dietary-treated patients attending the IEM Clinic, and Dr. Ward monitors the PKU patients and their families at the U.T. Boling Center weekly. Mississippi. Genetic associates include an ABMG Certified Genetic Counselor, and two Genetic Nurses, providing additional family services to

patients. Outreach clinics are located in Jackson and Arlington Developmental Center, Arlington, TN. This Center has the following genetic laboratories: Clinical Cytogenetic and Molecular Cytogenetic Laboratory; Inborn Errors of Metabolism Laboratory and Molecular Genetics Laboratory.

All faculty and genetic associates participate in didactic and clinical training to medical students, pediatric, medicine-pediatric and family practice residents, fellows, faculty, primary care providers, public health professionals, and the public. Future expansion of Genetic Services includes the enhancement of existing presymptomatic genetic counseling services, participate in initiatives for treatment of storage disorders (Gaucher disease ongoing for 10 years, addition of Fabry disease, MPS-I, and GSD-II collaboration). Continue to forge linkages with non-pediatric departments on campus (Medicine, Family Practice), the basic science molecular resource centers, and to expand Genetic Service Training of primary care providers. Increasingly develop strategies for the transfer of information to primary care providers.

E) The Center for Child Development, Department of Pediatrics, Vanderbilt University Children's Hospital. The Center for Child Development, directed by Dr. Robin McWilliam, provides follow-up services for children with developmental disabilities. Outreach activities include a) TRIAD (School Contracts for Autism Services), b) the National Individualizing Preschool Inclusion Project, a U.S. Department of Education Office of Special Education Programs funded effort to develop inclusive classrooms and to train teachers and students, and c) Natural Environments in Early Intervention, a model for delivering early intervention in natural environments. The center's services are family-oriented.

Additionally, research activities include the assessment of these programs as well as NICHD and U.S. Department of Education funded projects to measure core skill deficits in young children with autism, social orienting in autism, early screening for children with autism, engagement of preschoolers with disabilities, and empowerment of families of children with disabilities. Dr. McWilliam is working with the Tennessee Department of Education with its Tennessee Early Intervention Services program (Individuals with Disabilities Education Act), one of the target partners in this proposal.

F) The UT Boling Center for Developmental Disabilities (BCDD) at the University of Tennessee Health Science Center's College of Medicine in Memphis. Located near seventeen hospitals and rehabilitation programs, the BCDD is an interdisciplinary program whose mission is to improve the lives of individuals with developmental disabilities and their families through research, training, service, technical assistance, and prevention activities.

The BCDD's interdisciplinary clinical programs include participation from a broad range of health professionals including pediatricians, nutritionists, psychologists, psychiatrists, speech and language pathologists, social workers and others. In collaboration with Pediatric Genetics, the BCDD sponsors the Inborn Errors of Metabolism Program for West Tennessee that provides follow-up care to children with metabolic disorders in West Tennessee. The BCDD serves children with a wide array of developmental disabilities and special health care needs through clinical programs at the Center and in outreach programs such as High Risk Newborn Follow-up Clinics at the

Regional Medical Center and at Baptist Memorial Hospital, and Feeding Clinic and Craniofacial Anomalies Clinic at LeBonheur Children's Medical Center. The BCDD provides medical leadership to the largest TEIS-sponsored program in Memphis.

The BCDD has core support from the Administration on Developmental Disabilities as Tennessee's Center of Excellence in Developmental Disabilities Education, Service and Research. It receives support for the Maternal and Child Health Bureau for Leadership Education in Neurodevelopmental and Related Disorders.

The six partners represent the providers of services to children with special health care needs in this project. These partners have agreed to provide medical information on children with genetic and developmental disorders (with parent/guardian permission) to develop the database proposed in this project. Linkage to the database currently under development for infants diagnosed as the result of NBS and NHS were part of the planning efforts of this project.

These six partners represent three distinctive entities reporting to separate boards of directors. The UT Developmental and Genetic Center/Department of Medical Genetics, the UT-Memphis Boling Center for Developmental Disabilities, and the UT-Memphis Genetic Center all report to the University of Tennessee Board of Trustees. The UT Medical Center, Knoxville is separate from the University of Tennessee and reports to the Board of Directors of University Health Systems, Inc. The Vanderbilt University Division of Medical Genetics and Center for Child Development report to the Board of Directors of Vanderbilt University School of Medicine in Nashville.

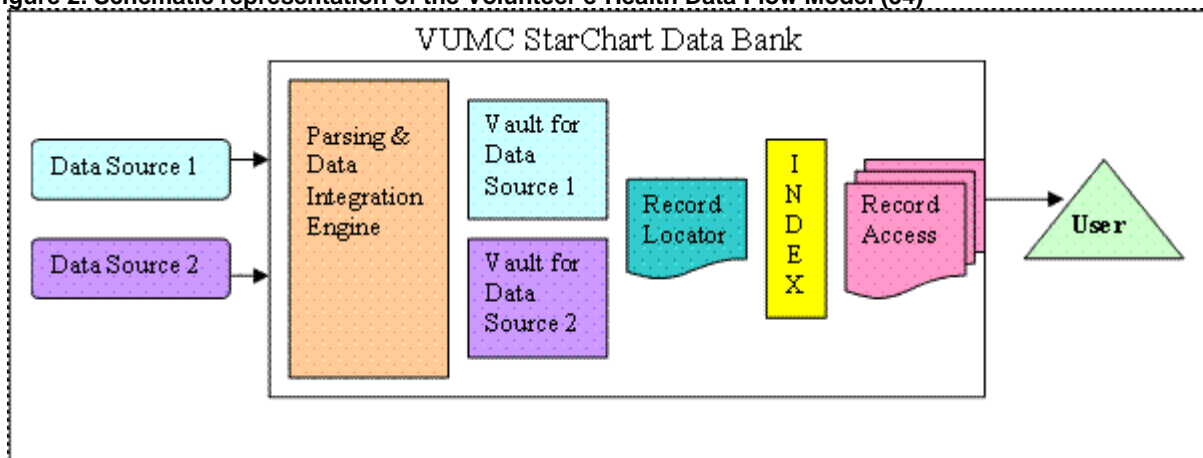
Additional collaborations include the Governor's Office on the Coordination of Children's Care that will provide the project with all TennCare (the state Medicaid program) records for all Tennessee participants during the past 10 years. The addition of the TennCare records will enhance both the data utilization and follow-up service delivery for CSHCN.

Further collaborations, currently in negotiation will involve the Tennessee Department of Health, which is a partner on the project supported by a grant funded by HRSA. The Tennessee Department of Education, Tennessee Early Intervention Services, supports the UT project and will be in a position to link its new database, serving children 0-21 under the Individuals with Disabilities Education Act, Sections C and D, when that database is completed in year 2 of the UT Implementation Project.

A major collaborative agreement has been reached with the Vanderbilt AHRQ funded Volunteer e-Health Initiative, a Demonstration project for the Memphis area. The UT project will develop database infrastructure on CSHCN for Tennessee state regions not covered by the Volunteer e-Health Initiative and will focus Volunteer e-Health resources towards CSHCN for the partners that are regionally and logistically linked with that project. The Volunteer e-Health Initiative, whose database development, linking, and access plan is outlined in the following Figure consists of a data vaulting system centered around the Vanderbilt University Medical Center's StarChart patient record keeping system. This system incorporates retail pharmacy transactions, instrument data exchange, imaging, laboratory test results, laboratory test orders, medications, client demographics, immunizations, interventions and procedures, clinical encounters, diagnoses, anatomical and physiological information, nursing information, genetic and protein information, structured text reports, chemical data, and financial/payment/billing records (54). Furthermore, the data flow process incorporates national standards adopted by the Consolidated Health Informatics (CHI) Initiative, including HL7 messaging, NCPDP script for pharmacy records, LOINC for laboratory test results, SNOMED for lab results contents,

diagnoses, and interventions. The Volunteer e-Health demonstration project focuses on the urban-rural counties surrounding Memphis, specifically Shelby, Tipton, and Fayette Counties. The project seeks to improve healthcare delivery to a large urban and rural population, including a large African-American population, and to reduce health care costs, especially with an emphasis on stabilizing the TennCare program (62-63, 73). This is being achieved through a partnership with the major hospitals in the Memphis area, including Baptist Memorial Health Care, Christ Community Health Center, Lebonheur Children’s Medical Center, Memphis Children’s Clinic, Memphis Health Center, Memphis Managed Care-TLC, Methodist Healthcare, Saint Francis Hospital, the Shelby County Health Department and Health Loop Primary Care Network, St. Jude Children’s Research Hospital, the Regional Medical Center, the University of Tennessee Medical Group, and the University of Tennessee Health Sciences Center (54). With the latter two participants, several hospitals with large pediatric service populations, and an established data infrastructure, the Volunteer e-Health Initiative has overlapping interests and opportunities for considerable synergy statewide with the UT-CHP project.

Figure 2. Schematic representation of the Volunteer e-Health Data Flow Model (54)



Incidence and Prevalence

The true incidence of children with special needs is unknown although it is estimated that at least 13 percent of all children are CSHCN (1-3).

The population of CSHCN that could be served by this project is based upon 209 confirmed genetic/metabolic cases in 2004, approximately 1,800 children with developmental disabilities served by TEIS annually (Wolraich et al., 1996), and 1,750 children identified with birth defects in 2003 (National Birth Defects Prevention Network, 2003). These estimates are most likely conservative, given that various estimates of the prevalence of disability among youth range from approximately 10 % to 30 % (Hollar et al., 2002; Horner-Johnson et al., 2003; McMillen et al., 2002; Topolski et al., 2003).

The prevalence and demographic distribution of the majority of birth defects and genetic disorders is unknown. We anticipate that the development of TN-CHP and the participation of genetic centers and child development centers from East, Middle, and West Tennessee in this

project will help delineate the prevalence and distribution of birth defects, genetic and metabolic disorders, and other developmental disabilities across Tennessee.

Methods

Database Linkages and Infrastructure Development

This system is being designed to provide HIPAA compliant access to critical health data, and where possible, secure the data to even higher standards than HIPAA mandates. Access to TN-CHP and pilot testing is controlled by security certificates, 128-bit encryption, user login access, and stored audit trails.

TN-CHP currently links NBS, NHS and electronic birth certificates. A pilot testing started in July, 2005 at four sites: UT Genetic Center, East Tennessee Children Hospital (ETCH) pediatric endocrinologist's office, and CSS case managers at the East TN Regional Office. An expansion of this database to include other CSHCN was started by December of 2005.

The servers are located at UHS Department of Information Services that is its own SSL secure certificate provider. Given that, the authorized user must have installed a public decryption key in conjunction with the private encryption key installed on the secure web server. Secure Socket Layer (SSL; i.e., https not http) is required for all web access to TN-CHP. Therefore, all data transferred between the servers and clients will be encrypted with 128-bit encryption. A HIPAA compliant user authorization form is required before a user account is created, and any account can be suspended immediately on will. The authorization reminds the user that it is a violation of Tennessee Code to release confidential information. Violations could result in sanctions and legal action, including prosecution. The child's guardian has ultimate control over who is authorized to view their child's health data.

System communications and oversight of the project have been maintained through the statewide Genetics Coordinating Committee (SGCC) a multidisciplinary committee, involved in the monitoring, review and ongoing evaluation of all aspects of this project. This committee has 37 members and includes 12 programs within the Tennessee Department of Health (TDH) (i.e., Maternal and Child Health, Children's Special Services (CSS), Genetics and Newborn Screening, Birth Defects Registry, Vital Records, Immunization Program, Cancer Registry, Community Education, TDH Office of Policy, Planning and Assessment) representatives from the Genetics Advisory Committee, representatives from the CSS Advisory Committee, representatives from the Tennessee Department of Education, Department of Mental Health and Developmental Disabilities, and the Division of Mental Retardation. Consumers organizations represented include the Alliance of Genetic Support Groups, Tennessee Voices for Children, Family Voices of Tennessee, and the March of Dimes.

The physical construction of TN-CHP system at UHS consists of three servers and verification of authorization via an additional secure certificate server. These servers employ the latest Microsoft operating systems and the web application is been developed using Microsoft .Net technologies. The data will be linked via the Oracle 9i data warehouse located on the same secure Local Area Network (LAN) as the web server, and both will be behind Cisco firewalls. Other data will be linked through the firewalls via ODBC linkages on an "ad-hoc" basis.

Web Interface

Whereas the above cited health records will be imported into the TN-CHP data warehouse in a “read-only” format, a utility will be introduced where a case provider can input and review consultations with clients. These reviews will use the accepted ICD-9-CM codes and will explore the use of children’s ICF (i.e., International Classification of Functioning, Disability, and Health) codes, which are currently under review from field tests by the World Health Organization, SNOMED and ICD-10 codes. The use of the codes will enable the clinicians, especially experts in developmental disabilities, to utilize standardized coding systems to track not only physical conditions but the overall functioning of the child for long-term periods. Furthermore, the interfaced clinician log will use the child’s system ID code to establish a separate field of variables in TN-CHP that can later be accessed by child system ID code, ICD-9-CM code, ICF code, SNOMED code, or ICD-10-CM code. While the latter two codes are not currently being used widely, and the ICF code currently in widespread use is an “adult” version (hence the recent development of a children’s ICF), these codes have been endorsed as standards by various public health and governmental agencies, including the United Nations, the World Health Organization, and the United States Federal Government Consolidated Health Informatics (CHI) Initiative.

With respect to children with developmental disabilities, the children and youth versions of the ICF are in review at WHO for subsequent field trials (R. Simeonsson, UNC, personal communication, 3-26-04). The ICF provides a systematic coding scheme for health information systems (ICF, 2001; Lezzoni & Greenberg, 2003). Additionally, it is designed to be complementary to ICD-9 and ICD-10 as classifications of morbidity. It addresses disability from both physical and contextual (environmental and personal facilitators/hindrances) factors (ICF, 2001; Simeonsson et al., 2000). The children’s ICF represents a valuable tool for clinicians to provide accurate long-term assessments of children with disabilities (Simeonsson & Leonardi, 2002).

Therefore, TN-CHP database infrastructure will consist of a primary “read-only” set of data linkages of information for each child collected from the Genetics and Child Development Centers with possible linkages to information from other database such as CSS, TEIS and Bureau of TennCare in addition to a secondary interactive and cumulative set of data entered by health care providers and case managers who are providing follow-up services to the child. Additionally, the use of HL7 messaging standards, the current existence of LOINC standards for NBS state lab results to the health department, and the incorporation of ICF, SNOMED, and ICD-10 diagnostic, follow-up monitoring codes will strengthen the infrastructure and enable ultimate connections with other state data warehouses as part of the National Health Information Infrastructure (NHII) initiatives, in conjunction with the Consolidated Health Informatics (CHI) Initiative. Additionally, we feel that the use of the standardized codes will greatly enhance the comprehensive provision of accurate services to children with special health care needs.

Results

Planning Activities

The project staff has been involved in extensive meetings and conference calls with the six key partners, and with potential partners at the Governor's Office on the Coordination of Children's Care, the Tennessee Department of Health, the Tennessee Department of Education (Tennessee Early Intervention Services – Individuals with Disabilities Education Act), and the Tennessee Division of Mental Retardation Services. The staff has also worked closely with many one-on-one meetings with the AHRQ National Resource Center members at the Vanderbilt University Center for Better Health, which is coordinating the AHRQ-funded Volunteer e-Health Initiative (<http://www.volunteer-ehealth.org/>) with 15 major hospital providers in the Memphis area of West Tennessee. These meetings and conference calls have resulted in significant involvement of all stakeholders and partners for this project. Memos of Understanding (MOU) have been signed among all partners for this project.

The project staff has also participated in conference calls organized by AHRQ, the AHRQ National Resource Center, SERGG Regional grant, and Connections Community of Practice. The staff also conducted frequent telephone calls and e-mail communications with key stakeholders. Two face to face meetings with members of the Tennessee State Genetics Coordinating Committee (SGCC) were held in November of 2004 and May 2005 and monthly conference calls were conducted with members of the subcommittees of SGCC. Significant input was received from members of the Consumer Involvement and Professional Education subcommittees.

An Information Technology Data Administrator, Mr. Robert Eubanks, was hired with funds from this grant. He has considerable database development and web application experience from his previous work at one of the grant partners, UHS, which is hosting the database for the planning and implementation projects. Mr. Eubanks has been working with the key data holders (i.e., Genetic Centers, Newborn Screening Data, Data from Child Development Centers) to develop the browser application for providers to test access to this database. Database and application servers have been purchased for the implementation of TN-CHP.

Major Successes

Major project planning successes have included the following:

- a) Data Sharing Agreements. The project has made arrangements with the three Genetic Centers and two child development centers, all part of the partnership, to provide data for the TN-CHP database. Additionally, the project will be incorporating data from Tenn. Care, the Tennessee Department of Health, and Tennessee Early Intervention Services.
- b) A database funded by HRSA has achieved linkages for three databases (newborn genetic/metabolic screening, newborn hearing screening and birth certificate records), has IRB and Tennessee Office of Information Resource small project approval, and is being

pilot tested in East Tennessee as a model for the development and implementation of TN-CHP.

- c) The TN-CHP planning project has received IRB approval from the Graduate School of Medicine at the University of Tennessee.
- d) Involvement of Physicians. Several groups of physicians, with a focus on pediatrics and family medicine, have agreed to participate with the TN-CHP project as database users and providers of services for CSHCN.
- e) Volunteer e-Health Collaboration. Very early in the AHRQ planning grant, the project staff made contact with Mark Frisse, Vicki Estrin, Jack Starmer, and Kevin Johnson with the Vanderbilt University Department of Biomedical Informatics and Vanderbilt Center for Better Health. This group received an AHRQ demonstration project award with matching funding from Tennessee Governor Bredesen to use the Vanderbilt University Medical Center StarChart medical records system as a secure record vaulting and access system for providers at 15 major hospitals and physicians groups in a three-county area surrounding and including Memphis. The goals of this project include complete data sharing of medical records between all health care providers in this metropolitan area in addition to surrounding rural areas, to improve healthcare delivery, and to reduce costs, particularly with rising Medicaid costs that are affecting theTennCare program and the state budget (62,63). This Volunteer e-Health Initiative is focused upon healthcare in general across the lifespan, and it stands to benefit from the current planning project's focus on CSHCN. Likewise, the current planning project can benefit from the secure vault system technology and hospital cooperative agreement experience of the Volunteer e-Health Initiative. Both projects envision collaboration and project leveraging activities that can speed the statewide implementation of an electronic child health profile once workable demonstration projects are tested and refined.
- f) TennCare Data. The project staff obtained permission to access all TennCare (state Medicaid) records for the past ten years of the program. These data will improve tracking of services provided to CSHCN in the state. The project staff will be working with the Governor's Office on the Coordination of Children's Care to analyze the TennCare and other databases in TN-CHP with reference to Child Find and monitoring of follow-up services to CSHCN.

Throughout these efforts, project planning has focused upon the following key concept: a workable electronic child health profile will be developed and tested as a possible model system that will benefit CSHCN and all children in Tennessee, from birth to adulthood. Furthermore, through collaborating with the AHRQ-funded Volunteer e-Health Initiative, the project seeks to develop a model electronic child health profile that can be used nationwide.

Outcomes

Progress has been made towards the following desired outcomes: (a) project partnerships between providers and holders of data have been established and (b) comprehensive expansion

of TN-CHP to increase service delivery to children with special health care needs has begun to be implemented. The TN-CHP secure web access to children's data from a single site is under development and will be able to provide more accurate, efficient delivery of follow-up services to children. Organizational changes will involve greater trust and communication between the holders of data in the Tennessee Departments of Health, Education, Bureau of TennCare, and Division of Mental Retardation Services.

The Award of the AHRQ Implementation grant 1UC1HS16133-01 that started on September 29, 2005 has provided the funds to implement this project.

Significance

The critical issues addressed by this project are:

1. Expansion of the health information system infrastructure across the state: This includes the linkage of relevant medical, health, and education data for each child and the establishment of partnerships among the various providers that interact with the children and provide valuable services for their physical and mental development.
2. Integration of systems of early identification with early intervention: Several state departments provide services for CSHCN, and the coordination of these services is a major challenge. The different state departments involved are: 1) The Tennessee Department of Education (TDE), including Tennessee Early Intervention Services (TEIS); 2) the Tennessee Department of Children's Services (TDCS) for children in state custody; 3) Tennessee Department of Human Services with the Supplemental Security Income Program; 4) Tennessee Department of Mental Health and Developmental Disabilities; 5) Tennessee Department of Health (TDH), including NBS and Genetic Services, CSS, Vital Statistics, Immunization, WIC, and other health related services. 6) the Department of Finance and Administration, which includes the Office of Information Resources (OIR), the Division of Mental Retardation Services (DMRS), and 7) the Bureau of TennCare, which administers the federal Medicaid funds through a system of managed care organizations (MCO). On November 1, 2000, these departments signed an Interagency Agreement to fulfill the requirements of Part B and C of the Individuals with Disabilities Education Act (IDEA). However, integration of services at the local level for each individual child is still a challenge since different case managers and service providers work with each child, and parents are often confused concerning the role of each agency serving their child.
3. Development of an electronic Child Health Profile (TN-CHP) that clearly identifies the primary chronic condition (e.g., specific metabolic disorder) for a child, a condition that might be overlooked by providers when the child receives services for other acute conditions. Current health record keeping procedures often code for billing purposes the treated condition(s) rather than the chronic underlying condition(s).
4. Access to health care providers of all relevant long-term health information (Child Health Profile) on a child from a single secure web source, freeing the provider from searching through multiple web sites, electronic records, and manual files to obtain information. To

date, no such Child Health Profile has been successfully implemented (Hinman, 2002a, 2004; Yasnoff, 2003).

5. Prevention of developmental disabilities through early diagnosis and treatment. Newborn screening for genetic/metabolic and hearing disorders offers tremendous health benefits to affected children and positive cost benefits to society. Early diagnosis followed by appropriate nutritional or medical interventions for serious genetic conditions such as galactosemia, phenylketonuria, MCAD or congenital hypothyroidism can make the difference between a child leading a relatively normal life or suffering mental retardation, long-term health care needs, or even dying. Additionally, several studies indicate that early hearing intervention at less than six months of age can improve cognitive functioning to within normal ranges by ages 3-4 for over 56% of children receiving early intervention services (Thomson, 1997; Yoshinaga-Itano, 1998a, 1998b).
6. Increase of communication between all aspects of the health care delivery system for meeting the patient's needs. The existence of data "silo" issues and non-cooperation between health care entities have hampered numerous efforts at linking public health databases (All Kids Count, 2003a, 2003b; CSTE, 2001).
7. Increase in the timeliness of follow-up services provided to children with special health care needs. With respect to many metabolic conditions, rapid response is absolutely critical. A delay of even a few days can make the difference between relatively normal development versus mental retardation or even death.
8. Reduction of lost cases by improved patient tracking and contact. This is more of a national problem given disparities between states in the implementation of public health entity cooperative agreements and database linkages. The development of state and national public health information infrastructures will require the use of standardized protocols and messaging systems that facilitate tracking of patients with serious conditions that require immediate treatment.
9. Implementation of quality assurance and evaluation of service delivery systems in electronic health information technology systems across the state. Although TDH is already promoting Comprehensive Systems of Services and State Performance Measures are being evaluated for many aspects of the MCH program, specific measures of services for CSHCN are needed.
10. Consumer participation in the planning, implementation and evaluation of services is an important aspect of this project: A very strong Consumer Involvement Subcommittee collaborating with the Ethics Subcommittee of the Statewide Planning Committee has identified needs and areas of concern to be addressed by this program.

Conclusions

The project planned for the expansion of the health information infrastructure in Tennessee with the novel development and linkage of complementary data warehouses from various sources. The resulting data linkages will greatly enhance the timely, accurate delivery of follow-

up services to children with special health care needs. The project will (a) improve health care delivery to children with special health care needs, (b) allow provider access to all of a child's records via a single web access instead of searching for disparate records from multiple sources, (c) reduce redundancies, medical errors, and record unreliability, and (d) enable long-term tracking of migration, morbidity, mortality, and services received for these children.

The collaborating partners provide services for children with special health care needs across the state and possess both the organizational and technical infrastructures to implement the project's aims and goals. This project addresses Healthy People 2010 objectives (94) including Objectives 16.1 (Reducing fetal and infant deaths), 16.2 (Reducing the rate of child deaths), and 16.14 (Reducing the occurrence of developmental disabilities). Additionally, this project will address Department of Health and Human Services Strategic Objectives (95-96) 3.2 (Strengthen and expand the health care safety net), 3.5 (Expand access to health care services for targeted populations with special health care needs), 5.1 (Reduce medical errors), 7.2 (Improve the development and learning readiness of preschool children), and 8.5 (Enhance the use of information technology in service delivery and record keeping).

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List of Publications and Products:

The project staff members have attended national conferences and have made oral presentations as well as poster presentations at these meetings. The following is a list of these presentations.

Hollar, D.W., Copeland, M.A., Lozzio, C., Blake, T.M., & Fleshood, (2004) Linking Child Health Databases: Pilot Results from Tennessee. Proceedings of the 10th annual CDC Maternal and Child Health Epidemiology Conference, Atlanta, GA, December 8-10.

Hollar, D.W., Copeland, M.A., Lozzio, C., Fleshood, L., Lainhart, R., Wilson, B., & Blake, T.M. (2004). Tennessee Child Health Profile (TN-CHP): An integrated data warehouse serving children with special health care needs. Proceedings of the 132nd American Public Health Association annual meeting, Washington, DC, November 9.

Hollar, D. (2005). Tennessee Child Health Profile (TN-CHP): Indexing and Data Matching. Presentation to the Public Health Informatics Institute Connections Community of Practice Unique Records Workgroup (Chair: Dave Ross, PhD). Atlanta, GA: Emory University Conference Center, March 29.

Hollar, D., Lozzio, C., Evans, M., & Eubanks, R.L. (2005). The Tennessee Child Health Profile Projects: Serving Children with Special Health Care Needs. Presentation to Tennessee Early Intervention Services (IDEA), Tennessee Department of Education, Nashville, TN: March 17, 2005.

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Lozzio, C (2006). Improving Quality Care for Children with Special Needs (invited). Connecting Kids through Child Health Information Systems. An Affiliate Meeting to the 5th Annual Forum for Improving Children's Health Care., Orlando, Florida, March 15-16.

Lozzio, C, Lamberth, M, Hollar, D, Eubanks, R. (2006 in revision). Integration of Newborn Screening and Health Information Systems. ACMG Annual Clinical Genetics Meeting, San Diego, CA, March 23-26