



The CHARM Report

~ *Child Health Advanced Records Management* ~

Summer 2006

CHARM Program Vision: *The CHARM Data Integration Infrastructure will be the information resource of choice for Public Health programs and Health-care providers that facilitates coordination of services, improves child safety, and health outcomes.*

- **Program Management Update** - CHARM recently submitted an application for the State Systems Development Initiative Grant. The notice of awards will be announced in September. Funds from this MCH grant, if awarded, will be used for CHARM data integration activities. For more information regarding overall program issues and schedules, contact Rich Harward at rharward@utah.gov or (801) 584-8529.
- **Technical Update** - The CHARM core data has been re-loaded from the first three participating programs (Vital Records, USIIS, and Newborn Hearing Screening) to address unsatisfactory matching results experienced on the initial load. Work continues on the interfaces with the Newborn Blood Screening and Baby Watch/Early Intervention programs, and the CHARM web interface. For more information, contact Mike Webb at mswebb@utah.gov or (801) 584-8209.
- **Public Health Informatics Institute (PHII) Meeting** – Christine Perfili and Rebecca Anderson recently attended the PHII Connections Site Visit in Rhode Island. The Rhode Island Department of Health showcased their child health integration system, KIDSNET. PHII provided an overview of their Business Case Model which will help states calculate the specific benefits and costs of integrating health information systems. PHII also distributed their Unique Records Portfolio which is a guide to resolving duplicate records in health information systems. Stephen Clyde, a consultant with CHARM, was a key contributor to the Portfolio. For more information, contact Christine Perfili at cperfili@utah.gov or (801) 584-8275.
- **CHARM Projects** – CHARM is currently working on three projects which include the Birth Certificate Project, the Genetics Project, and the CMV Project.
 - **The goal of the Birth Certificate Project** is to improve the timeliness and appropriateness of Early Hearing Detection and Intervention (EHDI) services to infants and their families and reduce the number of infants who could be lost to follow up. This includes children who missed a hearing screening at a hospital or opted out of the screening,

children who failed an initial screening and didn't come back for follow-up with an audiologist or failed two screenings and didn't complete the diagnostic, and children who have been lost in the system due to no address. This project will be accomplished with the integration of the EHDI Surveillance and Tracking System and the Electronic Birth Certificate program of Vital Records through the CHARM infrastructure. An interface is being built to access the CHARM system through Vital Records' OLIVER System. When parents/caregivers request a birth certificate for a child, Vital Records will connect with the CHARM server and the EHDI database to determine if a child has completed the hearing screening and/or diagnostic process. If this has not been done, an alert message will be sent to the Birth Certificate staff and they will forward the information to the parents/caregivers as well as verbally inform the parents and provide contact information for follow-up.

- **The specific aims of the Genetics Project are to:** 1) classify the etiology of the congenital hearing loss in infants by conducting prospective genetic evaluations of all babies with permanent hearing loss identified through the state's Early Hearing Detection and Intervention (EHDI) program, 2) determine the frequency of *GJB2* and two common mitochondrial mutations in this population, and 3) establish a model infrastructure linking genetic services to statewide EHDI programs using the CHARM infrastructure.
- **The principal goal of the CMV Project** is to determine the role of studying newborn blood spots for evidence of congenital cytomegalovirus (CMV) infection to understand the etiology of hearing loss in infants identified in Utah's Early Hearing Detection and Intervention (EHDI) program. This project will seek to: 1) determine the contribution of CMV infection to the occurrence of sensorineural hearing loss in infants, and 2) establish the role of polymerase chain reaction (PCR)-based methods in detecting CMV infected infants through analysis of newborn blood spots. Again, this project uses the CHARM infrastructure and the linkages between the EHDI database and the Newborn Blood (heel stick) Screening Program.

For more information about these projects, please contact Rich Harward at rharward@utah.gov or (801) 584-8529.

- **Data Sharing Agreements** – In addition to the signed Data Sharing Agreements with Vital Records, USIIS, Newborn Hearing Screening, and Newborn Blood Screening, the data sharing agreement with the Baby Watch/Early Intervention Program has been signed. Baby Watch/Early Intervention will be the next program to be integrated through CHARM. For more information, contact Christine Perfili at cperfili@utah.gov or (801) 584-8275.
- **CHARM Website** – The CHARM website has been updated. A new banner with photo images was designed and implemented, navigation was made more user friendly, the CHARM Reports (newsletters) and the most recent version of the CHARM brochure was added, and text was revised. Much thanks to Aryavash Aryazand for his assistance. For more information, contact Christine Perfili at cperfili@utah.gov or (801) 584-8275.