



Using Health Information Exchange (HIE) to Improve Care Coordination for Newborn Hearing Screening

“The Utah Department of Health Interoperability and Health Information Exchange Project expands the use of the existing state designated clinical health information exchange to improve care coordination for newborn hearing and cytomegalovirus screening.” - Christine Perfili, MBA, B.S.



Improving Newborn Hearing Screening

According to the Centers for Disease Control and Prevention (CDC), between one and three out of every 1,000 newborns are identified as Deaf or Hard of Hearing (D/HH).ⁱ The sooner D/HH children start receiving intervention services the more likely they are to reach their full potential.ⁱⁱ Early detection and intervention of D/HH infants helps to maximize their communication, language, and social skills development.ⁱⁱⁱ All U.S. states and territories have now established Early Hearing Detection and Intervention (EHDI) programs to help ensure that infants who are screened for hearing receive recommended follow-up through active tracking, surveillance, and coordination with clinical service providers and families.^{iv} For more information on EHDI programs, visit the CDC’s [Hearing Loss in Children](#) website.

National Early Hearing Detection and Intervention Goals

- ❖ Screen for hearing no later than one month of age
- ❖ Diagnose hearing no later than three months of age
- ❖ Enroll a D/HH child in early intervention no later than six months of age

According to the CDC’s EHDI Hearing Screening and Follow-up Survey, more than 95 percent of newborns are now screened for hearing.^v Despite high national screening rates, many test results are never shared with the relevant EHDI programs; consequently, many infants are lost to follow-up and may not receive important intervention services.^{vi} With support from the Office of the National Coordinator for Health IT (ONC), the Utah Department of Health facilitated a partnership between the Child Health Advanced Records Management (CHARM) Program, the Utah EHDI Program, the Utah Center for Health Data and Informatics Program, the Utah Health Information Network (UHIN), Intermountain Healthcare, and Multidimensional Software Creations (MDSC). The aim of the Utah partnership was to expand the statewide clinical Health



Information Exchange (cHIE) to support better communication and improved care coordination for newborn hearing screening and related follow-up care and services. The partners identified two use cases:

- 1) send clinical data, specifically Auditory Brainstem Response (ABR) and Cytomegalovirus (CMV) results from Intermountain Healthcare’s electronic health record to UHIN for delivery to the EHDI program
- 2) send hearing screening results from EHDI through the CHARM system, to UHIN and the Intermountain Healthcare network for care coordination.

The partners selected these use cases after reviewing data that showed that despite a 99 percent hearing screening rate in 2013, only 77.9% of infants that required a diagnostic audiological evaluation underwent ABR testing before three months of age. Data also showed that only 73.3 percent of children who were confirmed as deaf or hard of hearing were enrolled in early intervention services by six months of age. Also of concern was the finding that 13.2 percent of infants who did not pass initial hearing screening tests in 2013 were lost to follow up. In 2013, Utah’s reporting system for EHDI referrals was paper-based and relied on providers and EHDI staff to manually share information without the benefit of automated communication.

HIE to Support Infant Hearing Screening in Utah

The partners took advantage of Utah’s statewide cHIE and used Direct Secure Messaging to support timely identification of infants in need of further testing or early intervention services. A challenge the group faced was delays related to authorization and access for a vendor to assist with needed technical solutions. The Utah technical procurement process was longer than expected, which in turn extended the time required to complete all the project objectives during the relatively short grant period. The partners also spent significant time and resources working through interoperability issues. The partners found that developing and confirming a shared understanding of

Lessons Learned and Recommendations

- ❖ Plan for and allow ample time to navigate technical procurement protocols
- ❖ Allow ample time to work through data standard interpretation and interoperability issues
- ❖ Develop and validate a standard data dictionary and lexicon among all stakeholders to support HIE work
- ❖ The right data at the right time expedites follow-up care and coordination for a child.
- ❖ Experts in C-CDA , HL7, and EHDI standards made valuable contributions to the project
- ❖ Consider contacting **Utah’s EHDI program** to find out more about their lessons learned and accomplishments



the specific data that would be exchanged took time and required a number of iterations before finalizing. Different partners had different understandings of how to report and interpret preliminary hearing screening findings. The partners also worked to develop a common understanding regarding the indicators that support the need for further testing.

During the implementation phase, the partners received technical assistance support from the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) EHDI Program. CDC staff helped the partners review project workflow documents and synchronize the new workflows with national recommendations and guidelines. The partners found CDC's guidance and expertise invaluable in helping to interpret standards and develop a more accurate consolidated clinical document architecture (C-CDA) Progress Note Document to share hearing screening diagnostic results. CDC was an active partner working with Utah to implement these two use cases for the first time. Based on experience gained implementing these use cases, Intermountain Healthcare will be better prepared and able to interpret and apply C-CDA implementation guide standards to other use cases. Because the Utah Hearing Results HIE project is one of the first of its kind, CDC also benefited from understanding the challenges other states may encounter when implementing C-CDA and Health Level 7 (HL7) Version 2 (V2) message standards to support newborn hearing screening interoperability.

Looking to the Future

The Utah Hearing Screening HIE project went live in August 2016. Within three weeks of initial operations, EHDI had already demonstrated the value of immediate access to newborn congenital CMV screening results. The Utah EHDI program was able to get the right CMV test done at the right time for a child and coordinate follow-up care. As a result of immediate access to CMV and ABR results, the EHDI Program hopes to be able to reduce the percentage of infants who are lost to follow up and to increase the number of D/HH infants enrolled in early intervention prior to six months of age to over 90 percent—a significant improvement over the current rate of 73.3 percent of infants enrolled in early hearing intervention. In the future, UHIN and Intermountain Healthcare hope to apply their experience with C-CDA implementation to other use cases, such as immunizations, lab reports and surveillance. The partners also hope to expand the newborn hearing screening use case to include additional health care providers in Utah beyond Intermountain. Utah hopes to serve as an informational resource to other U.S.



states and territories interested in working on HIE projects to improve newborn hearing screening care coordination.

About the Utah State Department of Health CHARM Program:

[The Child Health Advanced Records Management \(CHARM\) Program](#) integrates several health care data bases, primarily within the Utah Department of Health, to create a consolidated electronic health record for children in Utah. This record provides a secure confidential way for authorized health care programs, partners, and providers to share public health data and track the health status of children.

ⁱ Centers for Disease Control and Prevention, Progress in Identifying Infants with Hearing Loss, MMWR; 2015; 64(13); 351-356.

ⁱⁱ Centers for Disease Control and Prevention, Early hearing detection and intervention among infants—hearing screening and follow-up survey, United States, 2005-2006 and 2009-2010. MMWR Surveill Summ. 2014;63 suppl 2: 20-26

ⁱⁱⁱ Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs Joint Committee on Infant Hearing, American Academy of Pediatrics

^{iv} Centers for Disease Control and Prevention, Early hearing detection and intervention among infants—hearing screening and follow-up survey, United States, 2005-2006 and 2009-2010. MMWR Surveill Summ. 2014;63 suppl 2: 20-26

^v Centers for Disease Control and Prevention, Progress in Identifying Infants with Hearing Loss, MMWR; 2015; 64(13); 351-356.

^{vi} IBID