

EHDI Advisory Report March 7 2014

Summary Progress Report for HRSA enclosed.

Also enclosed is the Work Plan submitted in a new application for the next 3 year grant cycle to continue with the project "Reducing Loss to Follow- up After Not Passing Newborn Hearing Screening". We again applied for 250,000.00 per year to continue funding the work of EPICS, Hands and Voices, the continued work of the 2 short- term follow up coordinators and the EHDI Coordinator salary.

Included is a brief of the progress for year 3 of CDC Development, Maintenance and Enhancement of Hearing Detection and Intervention Information (System EHDI-IS) Surveillance Programs. The Interim Progress report will be submitted April 4, 2014 that will include the work plan and evaluation plan for the next year.

The Annual EHDI Survey has been completed and submitted. It will document the work and results from 2012 and this will be published on the CDC EHDI website. Data Team to look at the results in March and develop a work plan and evaluation plan to address gaps in data.

CDC Brief

EHDI coordinator visits local pediatric practices and discusses issues with reporting . During this visit we learn that the provider has a check of to check hearing screening on the electronic medical record. Not all parents come with the information needed at the first well baby check. The provider suggests that they are also required to bring a second bloodspot card. They suggest that at the nursery both these documents should be placed in a red envelope with instructions . Then the PCP can request at the first well baby and the parent may more easily located the information to bring to the next visit if the consistent message is the information should be in your hospital paperwork in the red envelope. We discuss this with the bloodspot program and will be trailing this in this last quarter using a PDSA model.

Data run for 2013 indicates we are receiving 80% of records of screening results compared to the vital records birth rate. We have begun to collect birthing and screening results for homebirths. Homebirth providers now give information to parents about where to have screening done and 50% of homebirths were reported to the EHDI Program.

Goal 1

Goal 1: Develop and maintain the EHDI-IS to accurately identify, match, and collect data that is unduplicated and individually identifiable through the EHDI process.

Annual Objective 1.1

Ask Challengesoft to develop a unique identifier system so that if a duplicate record is entered it is identified immediately.

Objective Status Completed

Objective Description The data management team met with the Challengesoft engineer and this function was added to the data management system in order to reduce duplicate records. Needs Assessor and EHDI Coordinator have identified hospitals not reporting. The data management team met with the Challengesoft engineer a unique identifier function was added to the data management system in order to reduce duplicate records. Needs Assessor and EHDI Coordinator have identified hospitals not reporting and provided troubleshooting to help them to report monthly. EHDI Coordinator sends a monthly reminder that data is due. Data Manager notifies EHDI Coordinator by the 15th of each month if there is any missing data or issues with data. And the EHDI Coordinator follows up with hospitals to get the data.

Annual Objective 1.2

Birthing Providers will report results of screening on all births.

Objective Status On Track

Objective Description 16 of 30 hospitals provide information on all births by uploading to a secure website. This now includes the state's largest hospital UNMH. Other hospitals provide nursery logs or send a data disc with information. This information is sent to an epidemiologist in the department and is linked to vital records. This helps the program to identify any missing records. The data team (which includes the EHDI Coordinator Needs

Assessor Data Manager and Epidemiologist) meets weekly and the meetings have been with Challengersoft engineer. The meetings have helped the team learn the functions and capacities of Challengersoft and to map goals and objectives. Enhancements are requested and reports generated. The information is then gathered and analyzed according to the goals of the work plan and evaluation plan of this CDC Cooperative agreement.

Annual Objective 1.3

Develop a corrective action plan for/ with birthing providers and Audiologists to provide the missing records and to insure an accurate set of records is sent monthly.

Objective Status On Track

Objective Description Although we have identified some non compliance in faxing referrals and the accurate completion of the referral for (reporting babies that do not pass hearing screening) EHDl Coordinator is working with the midwife population and hospital screening programs for compliance and improvement in documentation under the HRSA Grant. Also being addressed in the HRSA Grant is improving loss to follow up through quality assurance of the information completed in the referral and follow up process. EHDl Coordinator will be providing data indicating number of births and number of screening results documented to each mid wife and hospital and requesting they audit files and send missing documentation. Rule for reporting have been sent to all birthing providers and posted on the website. The EHDl coordinator and the data manager have been providing individual training and technical assistance as data indicates missing documentation on a case by case basis. EHDl Coordinator has also begun outreach to primary care practices. This has resulted in a collaborative effort to improve reporting.

Annual Objective 1.4

Develop a Challengersoft program that will indicate to the Short term follow- up coordinator which babies need follow- up. In New Mexico some hospitals have contracted screening Providers that do follow up this will be reported electronically. Our Short term follow up coordinator will work with those hospitals that do not have this in place.

Objective Status On Track

Objective Description EHDl Coordinator is working with the Challengersoft engineer and the data learning team that includes the Newborn Screening Program Manager CMS Director, MCH Epidemiologist, NHS Needs Assessment Coordinator, Data Analyst and as a guest consultant the Business Manager from the Nebraska EHDl Program. The plan is to review the information flow, work flow forms and reports and to begin to create an interface to develop easier to use tracking and auditing function(s). This should be tested and then utilized this spring. As the paper referral is received the documentation is reviewed lead follow up coordinator for missing information. Calls are made to the hospital to collect missing documentation (fields on the referral form.) in the next three months The EHDl Coordinator and the Needs Assessor will be visiting hospital Programs to identify if this information can be downloaded electronically and the populated into the forms on Challengersoft. A report will be

generated by the EHDI Coordinator that can be sent to hospitals that will identify the record and the missing information. A second reporting function is being created to notify the follow up coordinators of a referral and to send a report of cases monthly. The function will also create a calendar event for the follow up coordinator based on the date of birth that will notify them that a call needs to be made at 1 month, 3 months and 6 months to remind caseworkers of these key events and to prompt them to do the follow up and reporting for those times. Additionally we plan to develop a user interface that will allow easier real time documentation. And recently we have learned through our information sharing relationship with Early Intervention that a number of children are being referred there and we have no history of some of the cases that are being referred. We plan to and link with a data base at Early intervention cases that have confirmed hearing loss and have been referred to compare that to our information following the case back to the hospital of origin to troubleshoot why we have had that loss to initial documentation.

Goal 2

Goal 2: Collect and report individualized demographic data (as defined in HSF Survey) for every occurrent birth about the child's status and progress through the three components of the EHDI process.

Annual Objective 2.1

By March 2014 submit 100% of data to the National CDC EHDI Hearing Screening and Follow-up Survey.

Objective Status Completed
Objective Description

Annual Objective 2.2

By June 30, 2014, develop and/or implement a process to monitor the quality and completeness of individualized demographic data (as defined in the HSF Survey) received from reporting sources.

Objective Status on track
Objective Description

Annual Objective 2.3

Review EHDI Data and collection process for 2012 (2011 data) and make changes needed to improve quality and completeness.

Objective Status On Track
Objective Description

Goal 3

Goal 3: Utilize findings from the analysis of EHDI data to guide the development and enhancement of the EHDI-IS and educate stakeholders about the program's successes, challenges, and future opportunities.

Annual Objective 3.1

Convene an internal work group and the Advisory Council to achieve this goal.

Objective Status on target

Objective Description An internal work group has been set up to work on this objective, although we have not met monthly at this point. The first half of the year has been devoted to the EHDI Coordinator, Needs Assessor and Data manager mastering the operation of the Challengersoft Program. Internally another Program Manager has experience with setting up Challengersoft functions to manage data and reports for her program. The EHDI Program Manager has been mentoring with her to learn user interfaces that can be adopted in the EHDI Program. One internal training has been offered to that included The EHDI Coordinator presenting with the Program Manager using Challengersoft, to the internal workgroup which included Newborn Genetics Manager and follow up Coordinator, CMS Program Manager, Epidemiologist, Needs Assessment Coordinator and Medical Director. Now the internal workgroup that includes the Data Manager, Epidemiologist, EHDI Coordinator, and Needs Assessor and the Mentor Program Manager are meeting weekly with Challengersoft engineers to institute new system functions and new enhancements.

Goal 4

Goal 4: Strengthen EHDI-IS by developing and implementing an evaluation plan and utilize findings to improve the system.

Annual Objective 4.1

Improved reporting of data sets NBHS NBGS Vital records and Part C records

Objective Status On track

Objective Description

Success Stories

Success Story 1

What did you do? Met with PCP providers to discuss issues with follow up

What did you accomplish? We learned that some providers are now linked electronically with their affiliate hospital and can see hearing screening results and make referrals directly to an affiliate audiologist.

What did you learn? How we can help is to continue to send written information about the importance of attending the appointment and instructions to reduce no shows.

Success Story 2

What did you do? Visited a PCP office that made a helpful suggestion

What did you accomplish? I met with the bloodspot program coordinator to discuss a collaborative effort to provide nursery staff with red envelopes and instructions to place second screening card and report of screening results in envelope. This is labeled to go to the first well baby check. PCP has a intake question including reminding the parent to bring this red envelope to the next appointment

What did you learn? WE are planning a PDSA to test this idea.

Success Story 3

What did you do? The EHDI Program formed a new alliance with additional uncharted stakeholders initiated by the need for families that choose homebirths to have community based, culturally competent, family centered hearing screening resources. The EHDI Coordinator together with members of the NM Midwives Association, The Maternal Child Health Program (which licenses and governs midwives), and the Office of Child Development, ECHO Initiative and the Newborn Hearing Screening Program formed a workgroup to explore hearing screening resource in the state.

What did you accomplish? Midwives account for 350 births per year in New Mexico. Midwives have not been reporting screening results and for the most part were unable to get babies screened within one month in the state. The barriers to screening were both cultural and logistical. At present midwives in New Mexico do not have screening equipment in their practices. The culture of a midwife client is that families that birth at home are not likely to go to a hospital program for screening. An alliance formed between EHDI coordinator and the Director of the New Mexico Head Start Collaboration Office and midwives. The Department of Health Maternal Child Health Manager, EHDI Program Coordinator, The Midwives Association and the ECHO Initiative members met by phone facilitated by the Head Start Collaboration Director and started discussions of how to collaborate. We opened a discussion that included the Early Head Start programs that may help meet the need in partnership with the ECHO Initiative. We will have our first statewide coordination meeting on April 1 inviting stakeholders for strategic planning. We will be mapping where Head Start has screening equipment, looking at training and needs for screening and reporting for Head Start Staff, linking the midwives to these resources, mapping statewide needs and resources for screening. We expect that midwives will utilize this program as a resource for screening and that this will also be welcomed by the Head Start Programs.

What outcomes or impact did you achieve? We expect that a plan will be drafted that will allow midwives to access screening at Early Head Start Programs. We expect this will improve the number of babies birthed at home that are able to get screening.

Did the success promote efficiency or effectiveness? Yes. Head Start is parent and family focused. Early Head Start Programs have and continue to work with the ECHO Initiative to train Head Start Programs around the state to do hearing screening. This new alliance offers mutual opportunities for HeadStart Early Head Start Programs to meet federal compliance issues for recruitment and community collaboration and for Midwives Practices by providing an untapped resource for their families. This also will provide for the EHDI Program a way to meet

the need of documentation of screening and reducing loss to follow up and loss of documentation of home birthed babies. (Families will be less likely to refuse screening)

Does the improvement link to or support a broader strategic plan, performance improvement plan, workforce plan or health improvement plan? Yes this does meet a broader strategic plan.

The EHDI Coordinator has been invited to sit on the Head Start Association Board and can foster an alliance between Maternal Child Health Title V and Head Start Health Initiatives.

Additionally, this is culturally a less clinical setting that may appeal to families that birth at home and also a resource for health, parent support and early childhood education for families as well as for hearing screening outcomes. This has also formed an alliance with the midwives that do homebirths. Midwives are becoming actively engaged in policy work with the Department of Health and already a notable increase in referrals and communication has been documented in the newborn tracking system.

What did you learn? That it is important to take the time to establish relationships with all professional organizations that may be part of the greater health community.