

INTRODUCTION

System development for Iowa's Early Hearing Detection and Intervention program is making significant strides toward assuring that all children in the state with hearing impairment are identified, referred and receive appropriate treatment. The Iowa Department of Public Health (IDPH) cooperative agreement with the Centers for Disease Control and Prevention (CDC) is the cornerstone for collaborative strategies serving this special population. The cooperative agreement provides an organizing framework and core resources contributing to significant accomplishments of the state's system. This application summarizes the strengths and accomplishments achieved thus far and identifies the lessons learned, along with the challenges still to be addressed in creating a sustainable EHDI system. Continued support from the CDC will allow IDPH to move the system to the next level of performance and assure that the infrastructure is in place to accomplish the goals and objectives of the proposed plan.

BACKGROUND AND NEED

Iowa's EHDI program is a collaborative effort of two projects, one funded by the CDC and one funded by the Health Resources and Services Administration (HRSA). The two projects work together seamlessly to achieve a comprehensive and coordinated statewide EHDI system. They are co-located at the IDPH Bureau of Family Health, Iowa's Title V program for maternal and child health.

The CDC project is administered by the Iowa Department of Public Health (IDPH). Under Iowa legislation regarding Universal Newborn Hearing Screening, IDPH is designated as the entity responsible for collection of hearing screening and diagnostic information.

The HRSA project is administered by Child Health Specialty Clinics (CHSC), Iowa's Title V program for children with special health care needs. The CHSC EHDI project focuses on

assuring that all infants and toddlers that are deaf or hard-of-hearing receive timely and appropriate follow-up services. The CHSC EHDI project also provides family support.

The IDPH cooperative agreement with CDC is central to Iowa's substantial progress in developing an EHDI system. Significant accomplishments include: 1) **state legislation** regarding universal newborn hearing screening, 2) **collaborative relationships** with key partners, 3) an established **advisory committee**, 4) statewide implementation of a **Web-based data system**, 5) reporting **protocols** that guide program development, 6) a **quality assurance** plan that promotes program consistency and accuracy, 7) a **program evaluation** that incorporates process and outcome objectives, and 8) a preliminary **sustainability plan** addressing the future of Iowa's EHDI program. The following section provides additional information on each accomplishment.

1) **State Legislation.** In 2004, the Iowa legislature mandated that every newborn be screened for hearing loss prior to hospital discharge. The law also requires that results of all screens, re-screens, and diagnostic assessments for children under age 3 be reported to IDPH. To date, 79 of 81* Iowa hospitals, all 10 Area Education Agencies (AEAs), and one private practitioner use eSP to report this information. (See Appendix B for a data flow chart.) Additionally, in July 2007, the Iowa legislature appropriated funds to IDPH to cover the costs of hearing aids and audiological services for uninsured and underinsured children.

2) **Collaborative Relationships.** As described previously, the IDPH EHDI project and CHSC EHDI project partner to achieve a comprehensive and coordinated statewide EHDI system. Co-location of staff from both projects assures daily collaboration. A memorandum of understanding allows ongoing data sharing between the two projects to facilitate follow up for

* Two hospitals were granted permission to continue submitting paper forms because they have less than 50 births per year and electronic submission would not be cost effective.

children who are missed or need additional screening and/or diagnostic assessment. The CHSC EHDI project contributes audiologists to provide technical assistance to the IDPH EHDI project.

IDPH also contracts with the Iowa Department of Education, Early ACCESS program (Part C) for referral and intervention services. Through Early ACCESS, Area Education Agencies (AEAs) across the state assure that children receive early intervention services for physical and developmental delays. IDPH's Early ACCESS liaison is co-located with IDPH and CHSC EHDI staff in the Bureau of Family Health.

Three bureaus within the Iowa Department of Public Health (IDPH) collaborate to address data sharing between EHDI and the Vital Records program.¹ The bureaus are Family Health (EHDI), Health Statistics (Vital Records) and Information Management.

The IDPH EHDI project collaborates with the Center for Congenital and Inherited Disorders (CCID), which administers Iowa's birth defects registry and bloodspot program and is also located in the Bureau of Family Health. The IDPH EHDI project and CCID have an informal agreement that addresses data sharing between the two programs.

The IDPH EHDI project partners with the Center for Disabilities and Development, Iowa's Leadership in Neurodevelopmental and related Disabilities (I-LEND) program for audiological training, technical assistance to EHDI screeners and audiologists, and assistance in developing EHDI protocols. An individual from the center also serves on the Iowa EHDI Advisory Committee. (See Appendix C for copies of MOUs and letters of agreement and support from collaborating entities identified in this application.)

3) **Advisory Committee.** Formed in 1994, the Iowa EHDI Advisory Committee directs the work of Iowa's EHDI system. Committee membership includes broad representation from

¹ Iowa's Vital Records program is located within the Bureau of Health Statistics at the Iowa Department of Public Health and will be referred to as "Vital Records" for the purpose of this grant.

public and private entities, constituents, and other key stakeholders that are affected by or involved with newborn hearing screening. (See Appendix D for a complete list of committee members and their constituencies). The advisory committee meets quarterly to assess program progress; provide input on project goals, objectives and activities; and raise awareness of the EHDI program and its importance to Iowa's children.

4) **Web-based Data System.** IDPH contracts with Optimization Zorn Corporation (OZ) of Dallas, Texas for its Web-based data system, eScreener Plus (eSP). The data system was selected through an in-depth analysis conducted as part of a competitive Request for Proposal process. Features of Iowa's eSP data system include: 1) specific results of birth and out-patient screening, audiological diagnosis, amplification (including the date of hearing aid fitting or cochlear implant surgery) and enrollment in early intervention; 2) identification of those lost to follow up, children who move out of state, or those who refuse further care at any stage of the process; 3) secure authenticated role-based Web access; and 4) extensive parental and provider notification functions (physician, family and medical record) through the automatic generation of letters and related documents.

A unique feature of eSP is its capability to search for unexpected clusters of infants with hearing loss in particular regions at specified times. In addition, the system can identify unexpected differences in EHDI screening performance of participating birthing hospitals or screening equipment. Individual providers can use the system to manage the care of selected infants during each progressive phase of the process, including tracking infants at risk for delayed onset and progressive hearing loss. The system includes a mechanism to audit actions taken by users or communications completed by users. It is searchable by user, site, patient, date range, or keyword.

The eSP data system is designed to address the issue of duplicate client records in two ways. First, to deter the creation of a second record for an individual child, eSP alerts screening facility staff if a child's medical record already exists at that facility. Second, to correct occurrences of duplicate records, eSP allows the duplicates to be merged into a single record.

5) **Protocols.** Iowa's EHDI protocols provide consistent standards for facilities and audiologists responsible for hearing screening and diagnostic reporting. The following protocols are currently in place to address issues such as personnel, facility responsibilities, test parameters and procedure, follow up, parental notification and refusal, and confidentiality: *Newborn Hearing Screening Protocol* (NICU and well baby); *Pediatric Audiologic Diagnostic Protocol*; and *EHDI High Risk Monitoring Protocol*.

6) **Quality Assurance.** Issues related to quality assurance are addressed on many different levels. The IDPH EHDI coordinator monitors newborn hearing screening results for children born in Iowa but living in other states. The coordinator reports these results to neighboring state EHDI coordinators in order to facilitate timely follow up. The project coordinator also collaborates with Early ACCESS (Part C) to assure follow up for kids that are missed or did not pass their hearing screen.

All eSP users are trained by IDPH EHDI staff using a training manual developed specifically to address the needs of the EHDI project and ensure consistent data collection and reporting methods. Training includes use of the token security access feature in eSP, which is considered to be among the most secure of Web access strategies. This feature incorporates secure authenticated role-based Web access, using a token security device to generate a six-character password at each use. To access eSP, the user enters the token password, followed by a

four digit soft pin known only to the user. This assures that only qualified personnel enter data into the system.

Quality assurance is also addressed through technical assistance provided by the CHSC EHDI audiologists. The audiologists monitor hospitals' miss and refer rates and offer assistance to those with rates higher than the limits set by the EHDI program. Technical assistance includes phone calls, site visits, instrument troubleshooting, and training in-services.

7) **Program Evaluation.** Iowa's EHDI program is currently evaluated using a combination of process and outcome measures. For process measures, the program's progress towards meeting its goals and objectives is tracked according to an established work plan and timeline. Outcome measures determine the extent to which project activities promote the national EHDI goals. IDPH EHDI staff developed a tool that evaluates the program based on selected national EHDI performance indicators. The evaluation tool provides baseline data and is completed annually to measure project progress. (See Appendix E for the evaluation tool.) The Iowa EHDI Advisory Committee reviews the evaluation components to assess project progress and guide plans for programming and sustainability.

8) **Sustainability plan.** In the fall of 2006, IDPH EHDI staff, with input from the Iowa EHDI Advisory Committee, developed a preliminary plan to address program sustainability. The committee identified the following four areas essential to creating a sustainable EHDI system in Iowa: 1) data system, 2) professional development, 3) public awareness, and 4) policy and advocacy. The preliminary EHDI sustainability plan is located in Appendix F.

Gaps/Needs

State legislation. Success achieved to date also highlights the need for further improvements in Iowa's mandate for implementing statewide reporting of newborn hearing

screening and diagnostic assessment results. Particular areas of focus include reporting requirements for risk factors and timeframes for reporting services other than the hospital-based newborn screen. There are still private audiologists and health care practitioners that do not yet routinely report this information within expected timeframes. These individuals must be identified and offered appropriate training. Additionally, individuals trained to use the Web-based data system, eSP, to report screening and diagnostic information need ongoing education and training to ensure consistent data entry and stay abreast of system updates.

Quality assurance. The primary focus of the IDPH EHDI project thus far has been statewide implementation of eSP. As a result, quality assurance activities have focused on implementation of the reporting software. Since initial implementation of eSP is now complete, IDPH will shift its focus to the quality and accuracy of data being reported. Currently there is no formal method for internal quality assurance monitoring at the local level. System evaluation demonstrates the need for strategies that concentrate on development and standardization of best practice policies and procedures that extend beyond currently established protocols.

Collaborative relationships – data sharing. IDPH currently shares data with key collaborative partners. However, we have identified barriers and must develop strategies to address them. For example, state-level interpretation of Part C federal privacy laws has been a major stumbling block for the EHDI project to receive child-specific referral information from Early ACCESS. Further, there are additional data programs that EHDI is aware of, but linkages are not in place to permit data sharing at this time.

Evaluation and sustainability. Process and objective measures evaluate specific aspects of the EHDI projects (i.e., progress towards the work plan and national performance indicators), but they do not provide a comprehensive evaluation of the entire EHDI system. A comprehensive

evaluation will assure that next steps for the project are relevant and realistic. IDPH EHDI staff identified the need for an individual with specific expertise in evaluation to conduct a comprehensive, objective evaluation. Further, the preliminary sustainability plan will need to be updated and finalized as the project moves forward.

The lessons learned from the accomplishments and gaps/needs discussed above were directly applied in developing strategies for this proposal presented in the following work plan.

PROGRAM PLAN /WORK PLAN

Based on the current status of the EHDI system, IDPH EHDI staff, with guidance from the Iowa EHDI Advisory Committee, developed four goals that will move Iowa's EHDI system forward over the next three years.

The goals, objectives and activities are identified below. More detailed information including a timeline, individuals responsible, and measures of effectiveness, can be found in the work plan and Gantt chart (Appendix G).

GOAL 1: Assure statewide implementation and further development of the EHDI surveillance system.

Objective 1.1: Through June 30, 2011, all current eSP users will receive continuing education and/or training on the eSP data system.

Objective 1.2: Through June 30, 2011, all individuals and facilities that provide hearing screening and/or hearing assessments will report the results to IDPH as required by law.

Objective 1.3: By December 2010, children with late onset or progressive hearing loss will be identified and follow up services will be provided.

Goal 1 addresses the implementation and further development of the EHDI surveillance system. The first objective states that all eSP users will receive continuing education and/or training on the eSP data system. To meet this objective IDPH EHDI staff will survey hospitals,

AEAs, and private audiologists to assess their training needs on topics such as the EHDI data system and quality assurance. Based on the results of this survey, EHDI staff will use existing trainings or new modules to provide continuing education and/or training to all users.

In the second objective, all individuals and facilities that provide hearing screening and/or hearing assessments will report the results to IDPH as required by law. The IDPH EHDI project will develop a statewide Pediatric Audiology Directory listing audiology service providers and resources available for children under age 3. While gathering contact information for the directory, IDPH EHDI staff will identify individuals and facilities that are not currently reporting, and therefore not complying with state law. Staff will notify these providers of the mandate and offer them reporting training.

The Iowa Department of Public Health (IDPH) EHDI coordinator will work with the IDPH legislative liaison and staff from the attorney general's office to amend the Iowa Code and Administrative Rules to ensure that all individuals/facilities that provide screens, re-screens, and diagnostic assessments for children under age 3 report the results as well as risk factors to IDPH within six days of service. Currently, only birthing facilities (birthing hospitals and birth centers) are required to report screening/assessment results within six days – other providers are not. In addition, neither birthing facilities nor other providers are required to report risk factors. As a result, only about half of the 81 birthing facilities currently report risk factors. This presents a challenge when trying to meet the national 1-3-6 goals and provide timely follow up with families.² Based on the recommendation for heightened surveillance of infants with risk factors discussed in the 2007 Position Statement by the Joint Committee on Infant Hearing (located at

² The National 1-3-6 goals are: All infants should have access to hearing screening using a physiologic measure at no later than **1 month** of age; all infants who do not pass the initial hearing screening and the subsequent rescreening should have appropriate audiological and medical evaluations to confirm the presence of hearing loss at no later than **3 months** of age; and all infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but at no later than **6 months** of age.

<http://www.pediatrics.org/cgi/content/full/120/4/898>), IDPH EHDI staff and the Iowa EHDI Advisory Committee feel strongly that the reporting requirements addressed in this objective should be mandated by law.

The third objective for goal one is that children with late onset or progressive hearing loss will be identified and follow-up services will be provided. To meet this objective, the IDPH EHDI project will hire a data assistant with expertise in Web-based data systems to conduct an in-depth review of the eSP components. The review will include the audiological assessment section to determine whether or not the system is able to identify children with late onset or progressive hearing loss. Based on the outcome of this assessment, IDPH EHDI staff will work with the CHSC EHDI staff and audiologists to enhance existing protocols, and a plan will be developed for reporting and follow up of children with late onset or progressive hearing loss. IDPH EHDI staff will also meet with staff from the Center for Congenital and Inherited Disorders to explore the feasibility of adding congenital CMV testing to the Iowa neonatal metabolic screening panel.

GOAL 2: Assure the quality and accuracy of reportable data.

Objective 2.1: Through June 30, 2011, technical support will be available to all hearing screening and diagnostic providers.

Objective 2.2: By June 2010, Iowa hospitals will have a miss rate of less than or equal to 1% and refer rate of less than or equal to 6%.³

Objective 2.3: By June 2010, the screening outcome of every occurrent birth will be ascertained.

Objective 2.4: By December 2011, a quality assurance review will be conducted at each Iowa birthing facility.

³ Target refer rates for the previous project period were 1% and 8%, respectively.

Goal 2 focuses on assuring the quality and accuracy of reportable data. The first objective relates to technical support for hearing screening and diagnostic providers. Technical support will be provided in three ways: 1) Child Health Specialty Clinics (CHSC) will provide audiology-related technical support to hearing screeners and diagnostic providers; 2) A quarterly EHDI newsletter, *Iowa EHDI News*, will continue to be distributed and posted on the EHDI Website at <http://www.idph.state.ia.us/iaehdi/>. Topics will include best practices, tips for screening, and resources for families and providers; and 3) eSP users, screeners, and audiologists will continue to have access to state-level technical assistance through a toll-free telephone number, e-mail and the EHDI Web site.

The second objective identified for goal 2 is that all Iowa hospitals will have a miss rate of less than or equal to one percent and a refer rate of less than or equal to six percent. A formal method for quarterly monitoring of hospital miss rates and refer rates will be developed. Technical assistance by phone or through a site visit will be provided to birthing facilities that do not meet the state standards for miss rates or refer rates. The technical assistance process will explore factors contributing to high miss rates (e.g., new screening personnel, old screening equipment, data entry errors, etc.) and establish a timeline for corrective action. Birthing facilities that do not consistently meet the state standards will be required to submit a written corrective action plan. IDPH EHDI staff will assist birthing facility personnel to develop monitoring procedures that will promote sustainable quality assurance at the local level.

In the third objective, the IDPH EHDI project will assure that the screening outcome of every birth will be ascertained by conducting a monthly data match between vital records reports and the EHDI Web-based system, eSP. Currently this is done manually, but planning has begun to create an electronic match. (See Objective 3.3 for additional information.) There are several

factors that might cause a facility to not report screening outcomes, such as: the child was transferred to another facility, removed from the parents' custody, adopted, or died. All birthing facilities have been trained on how to handle each of these situations, but sometimes fail to do so because these incidents occur infrequently or the facility does not have appropriate quality assurance checks in place. Using current baseline data, IDPH EHDI staff will work with the Iowa EHDI Advisory Committee to establish minimum reporting requirements.⁴ Facilities that do not meet the requirements will be required to submit a written corrective action plan to IDPH.

The final objective for goal two is to conduct a quality assurance (QA) review at each Iowa birthing facility. First, a QA subcommittee (consisting of Iowa EHDI Committee members) will develop and implement a best practices policy and procedure manual to guide local level QA. EHDI staff will conduct a site visit at each birthing facility using a standard QA review tool that will be piloted prior to full implementation. Following each site visit, EHDI staff will provide a written report that identifies strengths, weaknesses and program recommendations. EHDI staff will solicit evaluation/feedback on the manual and the site visit from birthing facilities in order to strengthen the process and outcomes.

GOAL 3: Facilitate data sharing, integration and linkage with related screening, tracking, and surveillance programs to minimize infants lost to follow up.

Objective 3.1: By June 2011, collaborate with the CHSC EHDI project to decrease the number of children lost to follow up by 5%.⁵

Objective 3.2: Through June 30, 2011, all babies born outside a birthing facility will be screened.

Objective 3.3: By June 2011, data sharing mechanisms between IDPH EHDI and the vital records program will be implemented.

⁴ Currently, on average, 9% of children born in Iowa do not have hearing screening results reported to IDPH.

⁵ Baseline (2007) for children lost to follow up is 26%.

Objective 3.4: By June 2010, data sharing mechanisms with the Early ACCESS system (Part C) will be implemented to monitor the status of early intervention services.

Objective 3.5: By June 2011, data sharing mechanisms will exist between the EHDI program and other MCH programs to minimize infants lost to follow up.

Objective 3.6: Through June 30, 2011, the Iowa EHDI program will collaborate with EHDI programs in other states to minimize infants lost to follow up.

Goal 3 relates to data sharing, integration and linkage to minimize the number of infants lost to follow up. The first objective builds on the strong collaboration between the IDPH EHDI project and the CHSC EHDI project. The two projects have an established MOU for ongoing data sharing to facilitate follow up for children who are missed, need additional screening, or need diagnostic assessment. The two projects will collaboratively establish protocols related to the follow-up process to strengthen the plan to address children that are lost to follow up. The plan will be evaluated based on its effectiveness and revised accordingly.

The second objective assures that all babies born outside a birthing facility will be screened. Two methods will be used to accomplish this objective: 1) EHDI will continue to include a letter and brochure regarding newborn hearing screening in the birthing packets provided to parents and professionals by the Vital Records program; and 2) EHDI will send an informational letter and brochure to the parents of infants born outside a birthing facility who have not been screened as identified in the data match discussed in Objective 2.3. (See narrative pg. 12 or the work plan in Appendix G.)

In the third objective, the EHDI program continues to work towards electronic data sharing with vital records. Until an electronic system is implemented, EHDI and vital records staff will develop an interim method for matching data files electronically. By the end of the

project period, data sharing will advance to include an import feature that will allow vital records staff to populate the EHDI data system (eSP) with demographics data. This will minimize birthing facility personnel's workload as they will no longer need to enter the same demographics data into multiple data systems.

The fourth objective under goal 3 relates to data sharing between EHDI and Early ACCESS (Part C). Once barriers related to data sharing have been identified, EHDI and Early ACCESS staff will establish a formal agreement to allow data to be transferred between the two programs that will identify children being served by both. A pilot data match will provide results that will be presented to the Iowa EHDI Advisory Committee to determine next steps.

The fifth objective under goal 3 addresses additional data sharing possibilities between EHDI and other programs. There are several programs that EHDI currently shares data with. These include the birth defects registry, the bloodspot program and the program for children with special healthcare needs. The program assistant for EHDI, who also serves as the program manager for the Child Death Review Team, records child deaths in eSP to avoid unnecessary follow up regarding hearing screening with families who have lost a child.

Data sharing with other department programs would benefit the EHDI program. These include, but are not limited to: Immunization; Women, Infants and Children (WIC); and the Title V child health data system. The EHDI program staff will explore new opportunities for data sharing during interactions with three existing IDPH entities: 1) the IDPH Data Integration Steering Committee (DISC) that convenes bureau managers quarterly to discuss data integration efforts, 2) the IDPH MCH Data Integration Team that convenes database managers quarterly, and 3) the IDPH Data Warehouse Project that offers a new platform for future data sharing.

The final objective under goal 3 discusses collaboration with the EHDI programs in other states. The IDPH EHDI coordinator will continue to collaborate with EHDI coordinators in neighboring states to share newborn hearing screening information regarding children born in one state, but living in another. This process facilitates timely follow up when needed. EHDI staff will network with other state EHDI coordinators at the annual national EHDI conference and by email and telephone, to identify best practices regarding data sharing to minimize the number of children lost to follow up. EHDI staff, with input from the Iowa EHDI Advisory Committee, will select and implement best practices, as applicable.

GOAL 4: Evaluate the Iowa EHDI system based on national EHDI performance indicators to establish a comprehensive and sustainable system that meets the needs of Iowa’s children and families.

Objective 4.1: By March 2009, assess the ability of the current data system to meet the needs of Iowa’s EHDI program.

Objective 4.2: By December 2009, determine which vendor product will most effectively provide the data necessary to meet the needs of Iowa’s EHDI program.

Objective 4.3: By June 2011, complete a comprehensive evaluation of Iowa’s EHDI system

Objective 4.4: By June 2011, finalize the sustainability plan for Iowa’s EHDI system.

All Goal 4 activities relate to program evaluation and sustainability. The first objective focuses specifically on the current data system, eSP. A data assistant will be hired to conduct an in-depth review of the Web-based data system components in order to assess the system’s current capacity as well as identify needs for enhancements.

In the second objective, program staff will determine which vendor product will ultimately provide the best fit for the Iowa EHDI system. The data system must accurately identify, match and collect unduplicated individually identifiable data on the following (at a

minimum): 1) **Screening results and demographics** (child date of birth, infant gender, maternal demographics, date of screen, and results); 2) **Diagnostic results** (ear-specific diagnosis and date of diagnosis); 3) **Intervention services** (date of referral to Early ACCESS early intervention services and date of enrollment in services); 4) **Loss to follow-up rates** (differences between key variables such as birthing facility, false positive rates, demographic differences and seasonal variations or other timing differences or geographic locations); and 5) Provide for long-term **sustainability and data integration** functions.

The current contract for a Web-based data system with Optimization Zorn, Inc. (OZ) is valid through March 2009.⁶ In preparation for this benchmark date, state-level staff will assess the data system, vendor customer service, and the vendor's ability to enhance the current system to capture necessary program data. EHDI staff will comply with state policy for vendor or internal development of customized software responsive to the results of program evaluation and supportive of long-term sustainability.

The following are minimum criteria for the EHDI software system. 1) Web-based access with secure exchange of information that allows specified entities access to limited parts of the system; 2) Technology compatibility with IDPH operating systems; 3) System compatibility with screening equipment; 4) Support for the seven national EHDI program goals; 5) User-friendly functionality within the system; 6) Collection and storage of required, mandatory, and optional data fields based on recommendations contained in the CDC Early Hearing Detection and Intervention Program Guidance Manual, February 2003; 7) Ability to generate specified reports and capacity to develop new reports as the program evolves; 8) Ability to generate letters and communicate results to families and care providers; 9) Ability to import and export data; 10) Case management component to assist with tracking and follow up; 11) Customization for

⁶ IDPH has the option to request a one-year extension to the current contract with OZ.

collection of additional fields, as requested by IDPH; and 12) Setup, training, and system technical support resources.

To accomplish the third objective, the IDPH will secure an outside objective evaluator who is qualified to conduct a comprehensive evaluation and analysis of its EHDI program. IDPH EHDI staff will also continue to utilize the existing evaluation tool to track program progress.

The fourth objective addresses sustainability of Iowa's EHDI system. The Iowa EHDI Advisory Committee will continue to play an integral role in reviewing and using the evaluation results to further enhance and sustain the EHDI program. The committee will build on the preliminary sustainability plan to determine the steps necessary to develop a sustainable EHDI system in Iowa. Technical assistant previously provided through the CHSC EHDI project provides the structure for formulation and further development of the formal sustainability plan.

COLLABORATIVE EFFORTS

Collaborative relationships play an integral role in the success and advancement of Iowa's EHDI system. The IDPH EHDI project and CHSC EHDI project work together seamlessly to monitor the effectiveness of the statewide EHDI system. The CHSC EHDI audiologists provide technical support to hearing screeners and diagnostic providers. They monitor miss rates and refer rates in the eSP data system to verify rates are within ranges established by the IDPH EHDI project and offer assistance with identified problems. CHSC EHDI staff is also responsible for reporting children needing follow up to Early ACCESS (Part C). Future collaborative efforts with CHSC EHDI staff will center around strengthening the system for tracking children lost to follow up.

IDPH has developed close working relationships with Iowa hospitals, birthing centers, Early ACCESS (Part C), Area Education Agencies (AEAs), and other audiologic assessment providers to facilitate statewide compliance with the mandatory newborn hearing legislation passed in 2004. As a result of these collaborative efforts, IDPH EHDI has third party agreements signed by all 79 birthing hospitals in Iowa with greater than 50 births per year, 10 area education agencies (AEAs), and one private practice audiologist, and all of these facilities are trained to enter screening and diagnostic information into the EHDI Web-based data system, eSP. IDPH is a signatory agency in the state's interagency agreement for Early ACCESS (Part C). EHDI staff refer children who were missed or did not pass their newborn hearing screen to Early ACCESS regional liaisons for follow up and intervention services. A previous data sharing project between Early ACCESS and EHDI failed due to changes within the Iowa Department of Education, the lead agency for Part C. Early ACCESS is designing a Web-based Individual Family Service Plan (IFSP) that the IDPH Early ACCESS coordinator (located with the EHDI coordinator in the Bureau of Family Health) is co-leading. The electronic IFSP will create possibilities for data-sharing with related programs such as EHDI.

The Iowa EHDI Advisory Committee meets quarterly and guides program planning, implementation, evaluation, and sustainability. Meetings also provide structured networking opportunities with key partners.

Internal partners play an important role in Iowa's EHDI system. The electronic Iowa Vital Records System (IVRS), located in the Bureau of Health Statistics, was implemented on January 1, 2007. The availability of the IVRS electronic birth certificate has improved the IDPH EHDI project's ability to verify that all occurrent births and screening results have been entered into eSP. However, the verification process is currently accomplished using a manual system.

IDPH EHDI staff will provide leadership for the development of an interim automated data matching system, including home births and birth record updates, until a more sustainable data integration plan can be implemented.

In 2008, the Iowa Department of Public Health began preliminary planning for a data warehouse project. Staff from the data warehouse project has been informed that the bureaus of Family Health (EHDI), Health Statistics (Vital Records), and Information Management are interested in using the data warehouse platform as a base for an EHDI-IVRS data integration project. EHDI staff will monitor the evolving data warehouse project.

The Center for Congenital and Inherited Disorders (CCID) includes the Iowa Neonatal Metabolic Screening (bloodspot) program and the Iowa Registry of Congenital and Inherited Disorders (Iowa's birth defects registry). The center is located within the IDPH Bureau of Family Health (with the EHDI program). The IDPH EHDI project has an informal data sharing process with CCID and will explore ways to further collaborate in the future. This will include exploring the addition of cytomegalovirus (CMV) testing to the newborn metabolic panel. CMV exposure has been identified as a risk factor for hearing loss, and testing as part of the newborn metabolic panel will help to ensure that children receive timely follow-up care.

The EHDI program also collaborates with the Iowa Child Death Review Team (CDRT). The EHDI program assistant is also the CDRT program coordinator, which creates a fluent system for data sharing. This individual enters child death information in eSP, the EHDI data system, on a monthly basis. When a child's status is changed to deceased in eSP, any care provided before death is maintained in the record, but the child is removed from any future care path in order to prevent unnecessary communication with the family.

All major MCH data systems, including child and adolescent health, women's health, Child Health Specialty Clinics, Iowa Registry of Congenital and Inherited Disorders, immunizations, WIC, EHDI and Lead Poisoning Prevention participate in the Iowa Department of Public Health MCH Data Integration Team. These data systems are working together to minimize loss to follow up and explore data integration.

The Iowa Leadership in Neurodevelopmental and related Disabilities (ILEND) program is an interdisciplinary training program within the Center for Disabilities and Development at the University of Iowa. ILEND trainees contribute to the IDPH EHDI project by develop materials for parents, helping with data entry, participating in the training of hearing screeners, and assisting with conference planning.

The EHDI program's collaborating partners have been fully engaged in the planning for this application and are supportive of IDPH's efforts.

PROGRAM CAPACITY

Iowa's work to establish a newborn hearing screening system began in 1993. At that time, screening was voluntary and a majority (86%) of Iowa hospitals participated; however there was no mechanism in place for reporting results to the state or to ensure that the children were receiving timely follow up and support. In 2000, when the Iowa Department of Public Health (IDPH) received its first CDC cooperative agreement, several collaborative partners were already working on the state's EHDI system. These partners included a grass-roots advisory committee, the Iowa Departments of Health and Education (Part C), Child Health Specialty Clinics (CHSC), Area Education Agencies, and many hospitals with birthing centers. Many of the same collaborating partners participate in today's EHDI system. (See the collaborative efforts section of this proposal, pg. 17-20, for more information on aforementioned entities.)

Newer partners have also emerged. The Coordinating Council for Hearing Services in Iowa reviews all services that support the education of children who are deaf or hard of hearing. The council provides recommendations and advice to the State Board of Education and Board of Regents regarding effective and efficient services for these children.

The Iowa EHDI system has produced maximum results through integrated programming using braided federal funding. Iowa is fortunate to receive funding from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) for its EHDI system. (See the background/need – collaborative relationships section pgs. 2-3 for more information). The IDPH and CHSC EHDI projects act as a team to create a fluid system, maximize resources, and leverage funds. The Iowa EHDI system also receives funding from Early ACCESS (Part C) for data system components, interpreter services, and technical assistance. Each of these resources provides a contribution critical to the success of the state's system. Finally, the EHDI program has funds appropriated by the Iowa legislature in 2007 to cover hearing aid costs not covered by insurance. The program anticipates that similar funds will be appropriated during the current legislative session that ends in April 2008.

Iowa's EHDI system has continued to evolve over the years. Originally, there was no formal method for collecting newborn hearing screening, outpatient screens, or diagnostic assessment results; eventually all birthing facilities, audiologists, and other health care professionals reported results by paper; and today 81 birthing facilities, 10 Area Education Agencies, and one private practitioner report results electronically. (Refer to pg. 4 of this proposal for more information on the Web-based data system.)

The capacity of Iowa's EHDI program is evident not only through the progress made on screening, surveillance, and intervention, but also through the community awareness it has raised

and the public commitment it has garnered. Responses from the EHDI newsletter suggest that the community is undoubtedly more aware of and interested in early hearing detection and intervention in Iowa. Commitment from key partners at the state and local level, including those that serve on the Iowa EHDI Advisory Committee, is invaluable.

STAFFING AND MANAGEMENT PLAN

M. Jane Borst, R.N., M.A., will serve as the project director for the grant (.05 FTE). Ms. Borst is Iowa's Title V director and bureau chief for the IDPH Bureau of Family Health and has extensive experience working with MCH tracking and surveillance systems. Ms. Borst has been involved with Iowa's EHDI project since its infancy and has served for the past five years as project director for the CDC EHDI Cooperative Agreement. She also serves on the Iowa Council for Early ACCESS (Part C) and the Executive Committee of the state's interagency coordinating council. As Iowa's MCH Title V Director, Ms. Borst oversees the state contracts and agreements with Child Health Specialty Clinics for services to children with special healthcare needs.

Ms. Borst will oversee the administration and fiscal activities related to the CDC cooperative agreement and direct the project evaluation and sustainability plan. She will be responsible for ensuring that required reports and documentation are submitted to CDC. She will supervise the work of all project staff, and will be available to each position on a regular basis.

Tammy O'Hollearn, B.A., will serve as the project coordinator (1.0 FTE). Ms. O'Hollearn has served as the state EHDI coordinator for the last three years. In this role, she has developed working relationships with entities providing screening, diagnosis, and intervention in Iowa. She has provided leadership to move the system from paper to Web-based reporting of screening and diagnostic hearing assessments. She currently serves on the state Coordinating Council for Hearing Services in Iowa and the Iowa Public Health Association. Ms. O'Hollearn

will oversee all grant activities, coordinate with partner agencies, and continue statewide implementation of the Web-based data system. She will direct data design, collection, and program analysis.

Laurie Robison, MPH, will serve as the program assistant (0.5 FTE) Ms. Robison has served in this capacity for nearly two years. Her program responsibilities include developing materials for and establishing data base training schedules, writing protocols, and providing support to eSP users. Ms. Robison has a background in laboratory medicine and in hospital and clinic settings.

A data assistant will be hired to conduct an in-depth review of the Web-based data system components in order to assess the system's current capacity as well as identify needs for enhancements. At a minimum, the data assistant will have demonstrated expertise in business requirements for custom software.

Jinifer Cox will serve as support staff for the project (0.1 FTE). Ms. Cox's responsibilities include performing data entry, conducting quality assurance checks in the data system, and assisting in the development of the Pediatric Audiology Directory. Ms. Cox has worked with the EHDI program for four years and demonstrates a high level of detail in her work.

Debra Kane, Ph.D., R.N. will serve as the MCH epidemiologist for the project (.05 FTE). Dr. Kane is an MCH epidemiologist, assigned to the IDPH by the CDC. Dr. Kane will provide oversight for project evaluation and will be available for technical assistance. (See Appendices H, I, and J for organizational charts, job descriptions and biographical sketches.)

EVALUATION PLAN

Quality assurance and improvement is a primary focus of Iowa's EHDI program for the upcoming three-year project period. Objective 2.4 states that a quality assurance (QA) review will be conducted at each Iowa birthing facility. To meet this objective, a QA subcommittee consisting of Iowa EHDI Advisory Committee members will develop a best practices policy and procedure manual that will be distributed to all Iowa birthing facilities at the beginning of Year 1. As facilities work to implement the recommended policies and procedures, the QA subcommittee will develop a site visit review tool, which will be piloted first, and then used to conduct site reviews at each birthing facility. Site visits will be conducted in Years 2 and 3 by IDPH EHDI staff with assistance from CHSC EHDI staff and audiologists. A written report identifying strengths, weaknesses, and program recommendations will be provided to each birthing facility within 45 days of the site visit. Also during this time, IDPH EHDI staff will work with CHSC EHDI staff and audiologists to develop a QA sustainability plan for birthing facilities. This plan will assure that birthing facilities have the resources and guidance to conduct ongoing QA activities and monitoring.

Throughout the project period, progress towards the project's stated goals and objectives will be measured using a combination of process and outcome methods. For process measures, the project coordinator will monitor the project timeline and progress in achieving objectives by established dates. The Iowa EHDI Advisory Committee will review the progress of the cooperative agreement activities quarterly and formulate plans with the IDPH EHDI project director and project coordinator for completing activities according to the established timeline.

The outcome evaluation will measure the extent to which project activities promote the National EHDI Goals. On an annual basis, the project coordinator will evaluate the EHDI system using an evaluation tool designed specifically for this purpose. Outcome evaluation measures are

based on a selected set of the national performance indicators. Data from this project period will be compared to baseline data established in 2005.

A portion of the evaluation will focus specifically on the EHDI data system, eSP. The data assistant will assess the features and capabilities of eSP to determine existing data features that have not yet been used by the Iowa EHDI program. Based on the assessment, EHDI staff will determine whether additional data features should be incorporated into the program. The data assistant will also identify data elements required for CDC reporting that do not currently exist within the system. This information will be used when negotiating database enhancements with the current data vendor or when releasing a competitive bid leading to a new data contract.

Beginning in Year 2, an independent evaluator will be hired to conduct a comprehensive evaluation and analysis of the EHDI program. The project director, with input from the MCH epidemiologist, will oversee the evaluation process. Data from the ongoing outcome evaluation (above) will be integrated into this evaluation. Results of the comprehensive evaluation and analysis will be presented to the Iowa EHDI Advisory Committee for input and recommendations. The components of this evaluation plan will be: 1) incorporated into future programming; 2) used to guide policy and decision making; and 3) incorporated into the existing EHDI sustainability plan. As a result, Iowa's EHDI program will continue to make significant strides toward assuring that all children in the state with hearing impairment are identified, referred and receive appropriate treatment.