Project Title: Iowa Newborn Hearing Screening and Intervention: Assuring Follow-up
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PROBLEM: Some Iowa children zero to three who are deaf or hard of hearing are not identified or receiving appropriate follow-up services. Review of the early hearing detection and intervention system developed through prior Universal Newborn Hearing Screening and Intervention grants revealed that program improvements are needed to: 1) assure that all newborns are screened prior to hospital discharge; 2) assure that audiologic diagnoses occur before three months of age; 3) enroll children in early intervention (Part C); 4) link children to medical homes; and 5) provide family-to-family support. Deficits in any one of the above systems components may result in lack of appropriate follow-up. This project addresses MCH priorities regarding appropriate screening, linkages to medical homes, and family support.

GOALS AND OBJECTIVES: Project goals are items 1-5 as stated in Problem.
Objective 1.1: Reduce the percentage of missed screens to less than 1%.
Objective 1.2: Reduce the hospital refer rates to less than 8% in the well-baby nurseries.
Objective 2.1: Develop communication tools for hospitals to communicate results to parents.
Objective 2.2: Increase provider knowledge of Part C EHDI procedures and best practice.
Objective 3.1: Establish data sharing procedures between EHDI and Part C.
Objective 3.2: Assure that infants with congenital hearing loss have access to early intervention.
Objective 4.1: Establish a system to regularly monitor infants at-risk for late-onset hearing loss.
Objective 4.2: Develop best medical practice guidelines for Iowa's primary care physicians.
Objective 4.3: Inform EPSDT care coordinators of EHDI issues.
Objective 4.4 : Develop a plan for linkage with other early childhood system initiatives.
Objective 5.1: Assure parents have access to ongoing support through family organizations.
Objective 5.2: Develop and implement a Deaf and Hard of Hearing Mentoring program.

METHODOLOGY: All EHDI project activities will be integrated into current efforts of existing statewide systems and family organizations who are collaborating on this project, to promote knowledge, skills and abilities of families and providers. The result will be that EHDI procedures and protocols will be integrated into the systems' and organizations' practices. The EHDI Advisory Committee and key collaborators will be consulted throughout the project.

COORDINATION: Project success will depend on the collaborative effort of: Child Health Specialty Clinics (Title V for cshcn), Early ACCESS (IDEA, Part C), Iowa Departments of Public Health and Education, Center for Disabilities and Development (Iowa's Center for Excellence in Disabilities), the Iowa Medical Home Initiative, and family groups.

EVALUATION: A new web-based electronic system (eSP) licensed through Oz Systems will provide data elements that are compatible with Part C monitoring procedures. Families and providers will be surveyed. Practices of early interventionists will be reviewed during Part C monitoring. Educational events will have course evaluations.

KEY WORDS: follow-up, early intervention, newborn hearing screening, hard of hearing, deaf

## Program Narrative

## Chapter I Purpose of the Project

### 1.1 Description of the problem

Some Iowa children zero to three who are deaf or hard of hearing are not identified or receiving appropriate follow-up services. Approximately 38,000 children are born in Iowa annually. In their 2003–2004 End-of-Year reports, Iowa's Area Education Agencies (AEAs) and Early ACCESS (Iowa's IDEA Part C system) indicate that, statewide, 80 infants and toddlers ages zero to three are receiving services for the deaf and hard-of-hearing. Estimates of the prevalence of congenital hearing loss, available from states such as Rhode Island (Vohr et al., (1998) Journal of Pediatrics, 133, 353) and Texas (Finitzo et al. (1998) Pediatrics, 102, 1452) indicate about 2.5 per thousand babies are born with hearing loss. These estimates suggest that in Iowa, approximately 285 children ages zero to three should be identified as having permanent hearing loss. Clearly some of these children have not been identified and/or entered into early intervention services for appropriate follow-up.

From 1998 to present, Child Health Specialty Clinics (CHSC), Iowa's Title V program for children with special health care needs, has administered a Health Resources Service Administration (HRSA) grant to create a Universal Newborn Hearing Screening and Intervention (UNHSI) program in Iowa. During that grant cycle the foundation for Iowa's UNHSI was laid. Simultaneously, the UNHSI staff collaborated with key players from the Iowa Department of Public Health (IDPH) responsible for administering a Centers for Disease Control and Prevention (CDC) funded cooperative agreement whose purpose was to expand the early hearing detection and intervention (EHDI) system infrastructure, including developing a statewide surveillance system for EHDI data. Relationships of key stakeholders for the *prior* grant cycle

are graphically depicted in Iowa EHDI System Funding Sources and Key Stakeholder Diagram, Appendix A.1.

This proposal seeks to build on system components developed through that effort by focusing on objectives and activities that will assure that all infants and toddlers who are deaf or hard of hearing receive timely and appropriate follow-up services. Relationships of key stakeholders for the current project are described in Chapter VII Collaboration and Coordination and are graphically depicted in the EHDI Organizational Chart, Appendix E.1.

To understand the low number of the potential 235 Iowa children ages zero to three receiving follow-up services for hearing loss, program planners from the UNHSI and CDC grants recently conducted a status review of each system component of an optimal model of universal newborn hearing screening and intervention. Breakdowns in any of the system components could result in children ages zero to three being lost to follow-up. Those system components include: 1) All newborns are screened prior to hospital discharge; 2) Audiologic diagnosis occurs before 3 months of age; 3) Enrollment in a program of early intervention occurs before 6 months of age; 4) Children are linked to a medical home; and 5) There is adequate family to family support for all infants with a hearing loss. Results of the review showed that although Iowa has made significant progress toward achieving universal physiological screening, implementation of a statewide system for reporting those screening results and timely follow-up for appropriate services have been difficult to achieve. As a result, all infants who do not pass the initial screening test do not currently receive timely and appropriate follow-up services.

The following in-depth analysis of each system component identifies where further work is needed before that system component can contribute to assuring that all infants who do not pass the initial screening test do receive timely and appropriate follow-up services.

*1. All newborns are screened prior to hospital discharge.* Due to efforts of the prior UNHSI grant, Iowa Code now requires hospital screening and reporting of results. However, quality issues related to high referral rates and/or missed patients still exist. A new web-based data system was purchased by IDPH through the CDC cooperative agreement to increase the data collection, reporting and sharing capacity of the Iowa EHDI program. Due to delays in implementing a customized software application, current data have been collected via paper reporting forms since January 1, 2004, and are currently being entered into the web-based data system. Therefore, it is not yet known how many newborns in the state have had their hearing screened, how many of those referred returned for follow-up, how many were diagnosed with a hearing loss, or at what ages they received amplification and/or entered early intervention. The web-based data system will have the ability to produce reports of these data once the entry of paper forms has been completed. The Iowa Universal Newborn Hearing Screening law requires hospitals to communicate the results of the screening to parents in writing. However, there is not currently a standard system of communicating results to parents. Work is needed to identify and expand use of best practices in communication of results. Use of the required EHDI data system will allow hospitals access to standard letters for parents and physicians. These letters can be edited by IDPH to reflect best practices in communication.

Due to the reporting requirements of the Iowa Universal Newborn Hearing Screening law, identification and tracking of children with risk factors for hearing loss will be possible. Risk factors are not included in the required data, but most hospitals are reporting this information voluntarily. The new EHDI data system will allow the IDPH to track children with risk factors and ensure that they have access to follow-up services.

*2. Audiologic diagnosis occurs before three months of age.* Part C monitoring data revealed that further communication between the Early ACCESS providers (Part C) and audiologists regarding best practice protocols and roles and responsibilities is needed. Representatives of audiologists on the EHDI State Advisory Committee report that many audiologists in the state feel unprepared to serve very young infants.

*3. Enrollment in a program of early intervention before six months of age.* Following the passing of Iowa's Universal Newborn Hearing Screening bill, the Early ACCESS (Part C) system became more active in ensuring enrollment of deaf and hard of hearing children in early intervention services. Iowa's EHDI program and the Early ACCESS system have worked closely together to develop procedures to increase the number of children with diagnosed hearing loss identified and enrolled in early intervention services. However, recent Part C monitoring data show there continues to be some confusion among families, Part C service providers, and service coordinators regarding referral procedures, eligibility criteria and responsibilities. Additional education and technical assistance is required throughout the state to correct this confusion. Comments from educators in the Part C system attending continuing education events have indicated a need for obtaining information through continuing education courses regarding children who are deaf or hard of hearing, from identification through early education.

*4. Linkages to a medical home.* Iowa Code requires that primary care physicians be notified of the results of the newborn hearing screening. While significant education efforts have been conducted with the American Academy of Pediatrics through the EHDI Chapter Champion, analysis of provider practices indicates that many pediatricians are not yet consistently integrating best practice protocols into their daily practice. Emphasis to date has been on reaching pediatricians, not family practice physicians. Due to Iowa's rural nature, some

communities do not have access to pediatricians, rather family physicians serve infants and toddlers in these communities. Children with special health care needs may also be served by public health nurses and pediatric nurse practitioners but minimum EHDI effort to date has been targeted to those practice groups.

*5. Family to family support for all infants with a hearing loss.* The level of families' knowledge regarding their rights to accessing the early ACCESS system and of follow-up options often impacts how successfully their child receives follow-up services. Review with family members of children who are deaf or hard of hearing indicate there is variation throughout the state regarding the content families of newly diagnosed infants and toddlers receive explaining communication options and resources. Families also self-report that they do not consistently receive services delivered according to family-centered principles.

1.2 Rationale and evidence supporting proposed interventions (Interventions are described in Chapter V.)

Using current hospital screening data to identify where over or under refer rates are occurring will allow state technical assistance resources to be targeted more effectively. Screening protocols will assure standard practices throughout the state and decrease false positive rates. The availability of screening loaner equipment will assure coverage when hospital screening equipment malfunctions and result in fewer missed screens.

Identifying children as early as possible is crucial to assuring optimum speech and language development and academic achievement. Iowa is a birth mandate state and as such, Early ACCESS is required to provide a free and appropriate education for children ages zero to 21 at no cost to families. Training Early ACCESS staff, including audiologists, regarding EHDI procedures will assure they deliver services early in the child's life, according to best practices

and family-centered principles. Assuring appropriate literacy levels and the translation of written EHDI materials will increase populations that are informed. Connecting families to Early ACCESS staff who are well-trained in EHDI protocols, will assure families receive the services to which they are entitled. Linking families to medical homes assures there is timely and continuous follow-up when providers are well informed of EHDI procedures.

The Maternal and Child Health Bureau recognizes family to family support as a crucial element of quality health care systems. The potential for networking and advocating for policy improvements is strengthened when family organizations for deaf and hard of hearing children join with other family organizations for children with special health care needs or disabilities. CHSC and the IDPH Bureau of Family Health support the mission of MCHB and work to incorporate family-centered practices into all child health programs. Providing deaf or hard of hearing mentors to families will assist families in knowing all communication options for their child. The EHDI parent consultant will be a valuable resource to assure that families become decision-makers at all levels.

1.3 Anticipated Benefit

No single activity of any system component can assure that all infants who do not pass the initial screening test receive timely and appropriate follow-up services. However, the combined activities of this project present a comprehensive plan for that assurance. Resources in this application will strengthen existing components of Iowa's EHDI system. Although newborn hearing screening occurs in all Iowa birthing hospitals, additional technical assistance will develop quality screening programs that result in follow-up and appropriate culturally competent intervention services.

This project will target resources to improving the knowledge, skills and abilities of early intervention providers for children ages zero to three who are deaf or hard of hearing. Some EHDI written materials currently exist, but this project will develop ongoing mechanisms to link families to one another and to comprehensive information sources. This project will develop a system for more comprehensive family-to-family support, with emphasis on using family-centered delivery practices and activities to reach minority groups. Collaboration with primary care physicians will be enhanced by partnering with Iowa's Medical Home Initiative and by continuing work already begun by the American Academy of Pediatrics' Chapter Champion. Coordination of all these efforts will assure that infants and toddlers receive appropriate follow-up services and enter an early intervention program in a timely manner.

Many of the project's goals will be sustained after the grant expires because collaborating stakeholders will build procedural changes into their respective systems, as further described in the Goals and Objectives, Methodology and Collaboration and Coordination sections of this application. Grant activities are designed to increase knowledge, skills and abilities of staff within hospitals, Early ACCESS (Part C), CHSC, primary care physician offices, IDPH, and families. By the end of this grant cycle, EHDI requirements will become part of standards of care for existing state service systems. Financial support from partnering agencies for deaf mentors will be sought throughout this project. EHDI procedures, best practice protocols, printed materials for families, deaf or hard of hearing mentoring models, and family support models will be reproducible and available for sharing with other states as requested.

**Chapter II Needs Assessment**

2.1 Needs assessment activities conducted to determine proposed activities.

The IDPH is currently implementing a new web-based electronic reporting system, eSP, licensed through Oz Systems. As the system is implemented, key data elements will be available to guide project development. Areas of specific interest, include but are not limited to: hospitals with high false positive rates; hospitals with under refer rates; children at-risk for late onset hearing loss; completion of follow-up screens; children with positive follow-up screens; children without a medical home; out-of-state residents born in Iowa hospitals; referrals between Area Education Agencies.

On October 7, 2004, the Iowa Early Hearing Detection and Intervention Advisory Committee met to discuss the status of the current statewide system and potential activities to assure that all children who do not pass the initial screening test receive timely and appropriate follow-up services. The Iowa EHDI Advisory Committee Members are shown in Appendix F.1. Recommendations of the EHDI Advisory Committee are included in this grant proposal.

Needs of professional communities for continuing education were surveyed through course evaluations after each continuing education opportunity provided during prior project periods. The project director of the prior EHDI HRSA grant also met with AEA hearing team supervisors three times per year and distributed continuing education needs questionnaires at those meetings. Results showed that professionals felt they needed more training in diagnosis of hearing loss in infants, hearing aid fitting schemes for infants, causes of childhood hearing loss and medical management, and listening activities to suggest to families.

Preliminary review of hard copy data showed that some Iowa screening hospitals have newborn hearing screening referral rates as high as 20 to 30 percent. Screening program quality is crucial to effective follow-up programs. High false positive screening results can result in delays in availability of diagnostic appointments and a casual attitude about the urgency of

follow-up among families and primary care providers. From this data it is clear that further training and technical assistance is required to improve screening program quality and minimize referral rates. This will provide access to diagnostic and intervention services to those infants who really need them.

2.2 Addressing specific barriers in Iowa

Early ACCESS is undergoing statewide system and geographic boundary changes that have delayed the communication exchange with hearing screening programs. Because of these delays, many screeners in the state still have a lack of understanding of how to refer to Early ACCESS and are not using newly released referral protocols.

Iowa is a rural state with one of the highest percentages of two-working-parent families in the nation. Follow-up services must be offered at times convenient to families and in places where transportation is not a barrier. Due to the low incidence of deafness or hearing loss, and the rural nature of Iowa, families with deaf or hard-of-hearing children may feel isolated from other families of children who are deaf or hard of hearing.

Cultural barriers exist in serving ethnic minorities, particularly Iowa's growing Hispanic population. Few professionals are bilingual, few written family educational materials are available in other languages and few professionals understand cultural differences in attitudes toward hearing loss and medical professionals. Iowa has an Amish population with high incidence of hearing loss and cultural beliefs that cause a high refusal rate for screening and/or services. Communication with Amish Elders will be pursued to identify solutions.

Data collection issues and service issues arising from children living in states bordering Iowa continues to be a challenge. CHSC will work with the CDC project to address this issue.

## Chapter III Data Requirements

3.1 OMB Approved Performance Measures and Administrative Data Reporting

The applicant will report annually on all required Forms and Performance Measures as instructed and referenced in grant guidance as Appendix G (not required in this application). This project will partner with the IDPH data collection system already described in section 2.1. Part C data monitoring procedures and data collection tools will incorporate EHDI project data requirements.

## Chapter IV Identification of Target Population

4.1 Target Population

The primary target population for the activities proposed to improve screening are Iowa newborns. The primary target for follow-up activities are newborns who do not receive or do not pass the initial screening test, infants who are at high-risk for late onset hearing loss, and infants who are deaf or hard of hearing. Additional target populations for training and support services are the families of these infants, Iowa audiologists, Iowa Early ACCESS (Part C) service coordinators and early intervention providers, Early ACCESS program managers and grantees, teachers of children who are deaf or hard of hearing, and Iowa health care practitioners including pediatricians, family physicians, and public health nurses.

4.2 Services and Supports

Iowa has an extensive system of services and supports to overcome barriers to the full implementation of a sustainable system of universal newborn hearing screening, follow-up, and entry into follow-up services. These are described in Chapter VII Collaboration and Coordination.

## Chapter V Goals and Objectives

The overall outcome for this project is to assure that all infants who do not pass the initial newborn hearing screening test receive timely and appropriate follow-up services. As already discussed, multiple factors within each system component of an ideal service model affect that overall outcome. The ideal service model components are stated below as goals. Objectives and activities that will directly affect timely and appropriate follow-up within each of those goals are the focus of this project.

**Goal 1: All newborns will be screened appropriately prior to hospital discharge.**

**Objective 1.1** – By March 31, 2008, reduce the percentage of missed screens to less than one percent.

Activity 1.1.a - By March 31, 2006, develop newborn hearing screening protocols with the endorsement of the EHDI advisory committee and distribute protocols statewide to hospitals and audiologists.

Activity 1.1.b – By March 31, 2007, ensure sustainability of loaner screening equipment program and publicize the availability of this program.

Activity 1.1.c – Continually monitor hospital reports to determine which hospitals are missing hearing screenings at the birth admission and why.

**Objective 1.2** – By March 31, 2008, reduce hospital refer rates to less than 8% in the well-baby nursery.

Activity 1.2.a – Create data reports on ongoing basis to monitor hospital refer rates.

Activity 1.2.b – Offer technical assistance to hospitals with refer rates higher than 8%.

Activity 1.2.c – Educate hospital staff about reducing refer rates by submitting articles to the state EHDI newsletter on a semi-annual basis.

**Goal 2 All audiologic diagnoses will occur before children are 3 months of age.**

**Objective 2.1** – By March 31, 2006, develop communication tools for hospitals to use to communicate screening results to parents.

Activity 2.1.a – Revise standard letters available in EHDI data system to assure health literacy level and appropriateness.

Activity 2.1.b - Translate standard letters available in EHDI data system into additional languages as requested by hospitals and audiologists.

Activity 2.1.c - Develop, distribute and analyze a survey to determine parents' perceptions about the communication they received about the newborn hearing screening from the hospital and use the survey analysis to guide technical assistance to hospitals.

**Objective 2.2** - By March 31, 2008 increase AEA provider knowledge of Early ACCESS (Part C) EHDI procedures and Best Practice guidelines.

Activity 2.2.a - Provide training to each AEA region regarding Early ACCESS EHDI procedures and Best Practice Guidelines.

Activity 2.2.b - Review Early ACCESS regions' EHDI procedures and provide technical assistance to regions whose procedures are not adequate.

Activity 2.2.c - Monitor data regarding age of diagnosis and entry into early intervention and provide technical assistance to AEAs as necessary.

**Goal 3: All eligible children will be enrolled in an early intervention program (Early ACCESS) before 6 months of age.**

**Objective 3.1** – By April 1, 2006, establish data sharing procedures between EHDI and Early ACCESS.

Activity 3.1.a – Collaborate with CDC systems development grant efforts for web-based reporting, and provide financial support for site licenses.

**Objective 3.2** – By April 1, 2007, assure that infants with congenital hearing loss will have access to appropriate early intervention services.

Activity 3.2.a – Assure infants with congenital hearing loss are referred to appropriate services for fitting for amplification by 6 months of age.

Activity 3.2.b - Educate potential referral sources about Early ACCESS referral procedures.

Activity 3.2.c - Inform members of the Iowa Council for Early ACCESS, the EHDI Advisory Committee and the Title V grantee agencies of the Early ACCESS referral procedures.

Activity 3.2.d – Request that Early ACCESS regional grantees inform their regional councils of Early ACCESS referral procedures.

Activity 3.2.e - Include information about Early ACCESS referral procedures in letters to physicians regarding infants' hearing screening/diagnostic results.

**Goal 4: All families with children ages zero to three who are deaf or hard of hearing or are at risk for late-onset hearing loss will be linked to a medical home.**

**Objective 4.1** – By March 31, 2008, establish a system to regularly monitor infants who pass the newborn hearing screening, but are at risk for late-onset hearing loss.

Activity 4.1.a –By March 1, 2007, develop statewide protocols to provide periodic audiologic monitoring for infants at risk for late onset hearing loss, using the latest recommendations of the Joint Committee on Infant Hearing (JCIH) as a guide and obtain EHDI advisory committee endorsement of these protocols.

Activity 4.1.b – By July 31, 2007, partner with Iowa's AAP Chapter Champion, the Iowa Academy of Family Physicians, the Iowa Academy of Otolaryngology, AEA administrators, and

Iowa's Title V program for children with special health care needs to disseminate monitoring protocols to their constituent groups.

Activity 4.1.c – By July 31, 2007 present monitoring protocols to the Iowa Perinatal Conference and other meetings of providers of medical care to infants and toddlers.

**Objective 4.2** – By March 31, 2007, develop best medical practices guidelines for Iowa's primary care physicians, using materials provided by Iowa's AAP chapter champion.

Activity 4.2.a - Obtain EHDI advisory committee endorsement of the best medical practices guidelines.

Activity 4.2.b - Disseminate the guidelines to physicians and train them to implement these practices at annual meetings of the Iowa Academy of Pediatrics and Iowa Academy of Family Physicians.

**Objective 4.3** – By April 1, 2007, inform EPSDT care coordinators of EHDI issues.

Activity 4.3.a - Present EHDI procedures and resources at EPSDT Conference.

Activity 4.3.b - Submit article regarding EHDI procedures and resources to EPSDT newsletter.

**Objective 4.4** – By April 1, 2006, develop a plan for linkage with other early childhood system initiatives.

Activity 4.4.a - Collaborate with the Early Childhood Iowa Stakeholders and the Quality Services and Programs workgroup to ensure that EHDI issues are integrated into the Early Childhood Health and Education System.

Activity 4.4.b - Collaborate with the Department of Education and Department of Human Services to integrate protocols and procedures for children who are deaf and hard of hearing into the Early Learning Standards for children aged 0-3 in physical, social and emotional domains.

Activity 4.4.c - Provide updated information about EHDI to local Community Empowerment board members through newsletters and meetings.

Activity 4.4.d - Partner with the Iowa Medical Home Initiative to provide training and resources to medical home partner clinics' staff.

**Goal 5: All families with children ages zero to three who are deaf or hard of hearing will receive family-to-family support.**

**Objective 5.1** – By April 1, 2007, assure parents of Iowa's deaf and hard-of-hearing children will have access to ongoing support through family organizations.

Activity 5.1.a - Partner with the Iowa chapter of Hands and Voices to provide a parent consultant to the EHDI system.

Activity 5.1.b - Train advocates with the Iowa chapter of Hands and Voices on appropriate family support.

Activity 5.1.c - Collaborate with CHSC and Early ACCESS parent consultants to ensure that parents are informed about services offered by Hands and Voices.

Activity 5.1.d. - Work with Deaf and Hard of Hearing Summit conference planners to assure that EHDI issues are addressed.

**Objective 5.2** - By March 31, 2008, develop and implement a Deaf and Hard of Hearing (DHH) Mentoring program.

Activity 5.2.a –By March 31, 2006, plan, inform stakeholders, recruit and select DHH Mentors.

Activity 5.2.b – From April 1, 2006 through March 31, 2008, connect families with deaf or hard of hearing mentors.

**<u>Relationship to Healthy People 2010</u>**

Through Healthy Iowans 2010, Goal Statement 11-9, healthcare professionals will be focusing on increasing to 91% the number of children, including those with special health care needs, who have a medical home as defined by the American Academy of Pediatrics. Through improved communication mechanisms, this project will link children identified with deafness, hearing loss, or at-risk for late onset hearing loss to those medical homes. Objectives and activities in this project are also aligned with Healthy Iowans 2010 Goal Statement 11-4, which states, "to increase to 98% the percentage of newborns that are screened for hearing loss before hospital discharge" and its activity statements.

Outcomes data and reporting for this project will also contribute to systems planning within Title V programs. Data also have the potential to contribute to several performance measures in the Iowa Title V Block Grant Application: National Performance Measure (NPM) #4 – *The percent of newborns who are screened and confirmed with condition(s) mandated by their State-sponsored newborn screening programs who receive appropriate follow-up as defined by their State*; NPM #1 – *The percent of children with special health care needs age 0 to 18 years whose families partner in decision-making at all levels and are satisfied with the services they receive;* NPM #5 - *The percent of children with special health care needs age 0-18 whose families report that the community-based service systems are organized so they can use them easily; and* State Performance Measure (SPM) #13 - *Percent of children estimated as being at-risk who receive monitoring and follow-up services at age 12 months.* The project will contribute to this measure by collecting ongoing Part C monitoring data regarding feedback from families of children ages 0 to 3 who are deaf or heard of hearing regarding their receipt of family-centered care practice, their satisfaction level, and their involvement in decision-making at various programmatic levels.

## Chapter VI Project Methodology

The overall goal of this project is to assure that all infants who do not pass the initial hearing screening receive timely and appropriate follow-up services. This will be accomplished by completing all of the activities described in Chapter V Goals and Objectives within their prescribed timelines and monitoring whether or not their accomplishment results in improved performance for each goal. One new employee, the Project Coordinator, will be hired immediately to facilitate the day-to-day operations of this project, and will be located at central administrative offices of Child Health Specialty Clinics in Iowa City. In the initial stages of the project the Project Coordinator, Project Director and Principal Investigator will introduce the project to key stakeholder groups in Iowa, including the EHDI Advisory Committee, Maternal and Child Health Advisory Council, Iowa Council for Early ACCESS, Executive Committee of Early ACCESS, leadership and audiology staff of CDD, Medical Home Project personnel, American Academy of Pediatrics Chapter Champion, the state consultant for teachers of the deaf and hard of hearing, the full team of state Early ACCESS technical consultants, Iowa Hands and Voices Chapter, and CHSC regional health services coordinators and parent consultants and other parent groups. All stakeholder groups will understand the overall purpose and proposed timeframes of the project.

All project activities will be monitored by the Project Coordinator who will report to the Project Director. Activities will be implemented by the respective staff hired for the project and/or by the stakeholder group designated as a resource for that activity. Position descriptions describing roles and responsibilities and functional relationships of key staff are described in Appendix B. Accomplishments will be evaluated and monitored and annual program reports submitted as requested by HRSA. A Project Activities Time, Resources, and Evaluation Table

further clarifies the timeframes, resources, and evaluation methodology for each activity, Appendix A.4.

## Chapter VII Collaboration and Coordination

Effective collaboration between major statewide agencies and family groups in Iowa is vital to the success of this project. Visual depiction of the collaborative relationships for this project are shown in the EHDI Organizational Chart, Appendix E.1.

### 7.1 Child Health Specialty Clinics

The overall administration of the Iowa newborn hearing screening program is with the Iowa Department of Public Health with heavy support from the Title V Children with Special Health Care Needs (CSHCN) Child Health Specialty Clinics (CHSC). CHSC is the public agency in Iowa authorized by Title V of the Social Security Act to plan and deliver health care services for Iowa's children with special health care needs. CHSC provides gap-filling health care services and influences the service system infrastructure to deliver more effective, higher quality health care services. CHSC employs community-based pediatric nurse practitioners located in 14 communities throughout Iowa (Appendix A.2). CHSC regional centers are located in seven of the eight cities that house facilities for audiological diagnostic evaluation of infants. CHSC also contracts with community physicians and parents experienced in serving and raising children with special health care needs.

CHSC actively collaborates in Early ACCESS activities throughout the state, and one staff member also serves as a Technical Consultant for Early ACCESS. The CHSC Director is a member of the Iowa Council for Early ACCESS and its Executive Committee. Through that role, CHSC is able to advise and assist the Early ACCESS system. Staff members are well qualified in the area of care coordination, service coordination, and delivering services that are

family-centered and culturally appropriate. CHSC staff will assist with follow-up to children identified as high-risk for late onset hearing loss.

7.2 Iowa Department of Public Health

As mentioned in Chapter 1, through this grant, CHSC will coordinate efforts with other early childhood initiatives that are underway in Iowa. Specifically, this initiative will collaborate with activities of the CDC EHDI Cooperative Agreement with the Iowa Department of Public Health (IDPH). The focus of this Cooperative Agreement has been development of a statewide surveillance system for newborn hearing screening, rescreening, and diagnostic assessment results.

Contracts with local public health agencies providing Title V Child Health services require that the agencies be involved with the Early ACCESS system on a local and regional level. Their involvement includes child find, service coordination, participation on regional councils, participation on Individualized Family Service Plans (IFSP) teams and other relevant activities. The IDPH Early ACCESS Technical Consultant will continue to provide support to IDPH, Early ACCESS, and the EHDI program.

The state High Risk Infant Follow-Up program, under the direction of Dr. Herman Hein, provides a perinatal review group to visit state perinatal centers on a rotating basis.

7.3 Early ACCESS (Part C)

Early ACCESS is a federal program under IDEA, Part C. This system is a statewide, interagency collaboration between the Iowa Department of Public Health, Iowa Department of Education, the Iowa Department of Human Services, and CHSC (Title V, CSHCN). The purpose of Early ACCESS is for families and staff to work together in identifying, coordinating and providing needed services and resources that will help the family assist their infant or toddler

to grow and develop. Any Iowa infant or toddler, age birth to the child's third birthday (0-3), with a developmental delay or disability and their family may be served if determined eligible. Children served have a 25% delay in one or more areas of development or have a known condition that has a high probability of resulting in a later delay in development. Because hearing loss or deafness is a condition that has a high probability of resulting in developmental delay, these children are automatically eligible for Early ACCESS services. The Part C Memorandum of Agreement defines roles and responsibilites of each signatory agency (Appendix D.1). Currently the Area Education Agencies are the grantees (Appendix A.3).

7.4 Department of Education

The Iowa Department of Education (IDE) administers 12 Area Education Agencies (AEAs), which cover all of Iowa. In the 2003-04 year, Iowa employed 132 teachers of the deaf and hard of hearing (AEA and Iowa School for the Deaf combined) and 62 educational audiologists. Of the 132 teachers, 46 are employed by the AEAs and are the first to encounter students through Early ACCESS. Each screening hospital is served by an AEA, which provides supporting audiologists, supporting teachers of children who are deaf or hard of hearing, and home-based early intervention for infants and toddlers with a hearing loss.

7.5 The Centers for Disabilities and Development

The Centers for Disabilities and Development (CDD) is Iowa's University Center for Excellence on Disabilities (UCED). CDD/UCED provides medical and health-related services and supports to more than 3,500 individuals with disabilities, and to their families, each year. A wide range of disciplines are represented including audiology, medicine, nursing, occupational therapy, physical therapy, psychology, rehabilitation engineering, social work, and speech-language pathology. One lead audiologist will assist with authoring protocols and oversight for

quality control issues. Two CDD audiologists will provide statewide support services under this project for training and technical assistance.

Information dissemination resources include the Iowa COMPASS (Iowa's statewide information and referral service for disability-related issues) and Infotech (an information and referral service on assistive technology).

7.6 Parent Groups

Family organizations including Iowa Chapter of Hands and Voices, Parents as Teachers, the ASK Resource Center, Family Voices, and CHSC's parent consultant network will share information and participate in joint planning events to maximize family involvement and collaboration between families and professionals.

7.7 Iowa Medical Home Initiative (IMHI)

This MCHB funded project is in Year 2 of implementation in Iowa. Leaders of the AAP and FAAP serve on IMHI. The Principal Investigator for this grant is also the Principal Investigator for the IMHI.

7.8 Audiologists

There are at least nine audiologists in private practice or public institutions in the state that provide diagnostic audiologic services and hearing aid fitting services to children of all ages. This group has also supported newborn hearing screening by discussing each center's program with the pediatricians and nurses they visit.

7.9 Collaborative efforts that have already begun will be expanded

Early ACCESS (Part C) technical consultants representing the IDPH and CHSC will collaborate to identify and eliminate system barriers to effective collaboration between EHDI and Early ACCESS. Early ACCESS regional monitoring will include probes regarding EHDI

activities. In addition, each Early ACCESS region will identify staff members who can assist families to find and access follow-up hearing services. Early ACCESS Regional Liaisons will play a key role in publicizing the screening program through communication with the interagency representatives on their regional advisory boards.

The Principal Investigator, an Iowa pediatrician, will provide a link to community pediatricians and family practitioners statewide through his many connections at The University of Iowa and through professional groups and the Iowa Medical Home Initiative. The Maternal and Child Health Council, an advisory council for the State's Title V programs, will be consulted for input regarding appropriate stages of this program. This group includes consumers of maternal and child health services (including services for children with special health care needs) and an array of other public, private, and voluntary organizations concerned with the health and health-related issues of Iowa's children and families. The EHDI Advisory Committee (Appendix F.1), representing parents and organizations crucial to individuals who are deaf or hard of hearing, will continue to advise this system. The Iowa Council for Early ACCESS, a 30-member stakeholder group to advise the system of Early ACCESS, will also be consulted regularly regarding EHDI issues. Refer to Appendix F.2 for letters of support from the agencies, organizations, key public and private providers, consumer groups, and others who have agreed to support this project.

## Chapter VIII Administration and Organization

The Early ACCESS state participating agencies and CDD support Child Health Specialty Clinics (Title V, CSHCN) as the applicant for this grant based on CHSC's current relationship with Early ACCESS, Iowa Department of Public Health, CDD, Iowa providers, hospitals and specialty programs/clinics, the Iowa Medical Home Initiative, and key family support groups.

Relationships to other partnering agencies have already been described in Chapter 7 and are illustrated in Appendix E.1. Functional relationships of key personnel are described in Appendix B.

CHSC and CDD are all located under the University of Iowa organizational structure. Multiple agreements exist between CHSC, CDD, and IDPH for such things as Perinatal Review Committee, High-Risk Infant Follow-Up programs and others.

## Chapter IX Organizational Experience, Capacity and Available Resources

9.1 Capacity regarding activities to improve screening quality at birthing hospitals

Iowa has worked diligently over the past 10 years to establish first a voluntary newborn hearing screening system. These efforts resulted in the enactment of a legislative mandate (unfunded) that requires all birthing hospitals to screen. Currently, there are universal newborn hearing screening programs in all 89 of Iowa's birthing hospitals. Currently, 78 of Iowa's birthing hospitals use otoacoustic emissions (OAEs) and eight use automated auditory brainstem response (AABR). Only three of Iowa's 89 birthing hospitals are using a two-stage OAE/AABR screening protocol. To improve program quality by reducing false positive rates and perhaps by identifying children with auditory dyssynchrony, an attempt will be made to move more hospitals to a two-stage OAE/AABR screening program.

9.2 Capacity regarding connecting identified children to Early ACCESS (Part C) for follow-up.

Work of Early ACCESS (Part C) is currently focusing on early identification of eligible children. Identification of children with a hearing loss has been an important aspect of that work, and is included in statewide efforts. Part C early identification data for children who are deaf or hard of hearing will be provided by the current Early ACCESS grantees (AEAs). Each of Iowa's 12 AEAs employs between two and twelve audiologists to provide educational audiology

services to children ages 0 to 21. Audiology staff also work within the Early ACCESS system to assure procedures are followed and to improve the infrastructure of EHDI. Iowa COMPASS, an information and referral agency, is the Early ACCESS central point of entry and will be facilitating many referrals for children needing follow-up hearing services and provide data.

Iowa's Universal Newborn Hearing Screening law allows the IDPH to communicate hearing screening results to Iowa's Early ACCESS grantees. This provision has eased referrals from the EHDI program to the Early ACCESS system, and has improved communication and coordination.

9.3 Capacity regarding professional newborn hearing screening education in Iowa

Leadership from CDD audiology staff will facilitate continuing education for state audiologists. Other statewide educational events will be planned in collaboration with Deaf Services Commission of Iowa, Iowa Medical Home Initiative, Early ACCESS, Bureau of Children, Family and Family Services of the Iowa Department of Education, and other members of the Statewide EHDI Advisory Committee. The Early ACCESS Comprehensive System of Personnel Development work group will also include EHDI content in pre-service education recommendations.

9.4 Capacity regarding family support

Many family organizations already exist in Iowa including: ASK Resource Center, Parent Educator Connection, CHSC Parent Consultant Network, Family Voices, and a newly-founded chapter of Hands and Voices. A major job responsibility of the EHDI parent consultant will be to connect Hands and Voices to existing parent support groups. Request for ongoing support from the Iowa Department of Education and/or other programs will be requested to support Deaf and Hard of Hearing Mentors beyond the grant period. Service coordination training modules

developed by Part C (Early ACCESS) will be available to parent consultants and DHH mentors assigned to this project.

9.5 Capacity regarding provision of early intervention services

Once an infant in Iowa is identified as being deaf or hard of hearing, home-based early intervention services for children with hearing loss are provided primarily through each AEA. Each AEA hearing team includes audiologists and teachers of children who are deaf or hard of hearing. AEAs utilize IDEA Part C federal funds from IDE to support costs associated with requirements for referral, evaluation, assessment, and the Individualized Family Services Plan.

Each AEA has at least one teacher of the deaf and hard of hearing on staff. Several local education agencies (LEAs) have their own teachers on staff. In addition to teachers of the deaf and hard of hearing, most deaf or hard of hearing children also receive services, as determined by their IFSP/IEP team, from audiologists, speech-language pathologists, general education teachers, early childhood special education teachers, psychologists, social workers, physical therapists and occupational therapists.

9.6 Capacity regarding linking families to a medical home

The Web-based surveillance system now being implemented will allow for primary care physicians to be notified of hospital screening results. In some situations only the name of the birthing physician is available and it may not be the child's primary care physician/medical home. Systems development work in collaboration with the CDC surveillance project staff will be needed to address this challenge.

9.7 Capacity to collect and report individual level data from multiple sources

An electronic birth certificate (EBC) steering committee has been established to provide oversight to the design and development of the web-based electronic birth certificate system.

Newborn hearing and metabolic screening questions have been added to the worksheet that each birthing facility will complete as part of the EBC submission. Hospitals will be asked to indicate if the child was screened for hearing loss prior to discharge and to report the results of screening tests. Hospitals will also collect data on the number of metabolic screens completed and will be asked to submit the metabolic collection form number. The completion of these questions on the EBC will allow the metabolic and hearing screening programs to identify those children who were not screened prior to discharge in a more timely manner.

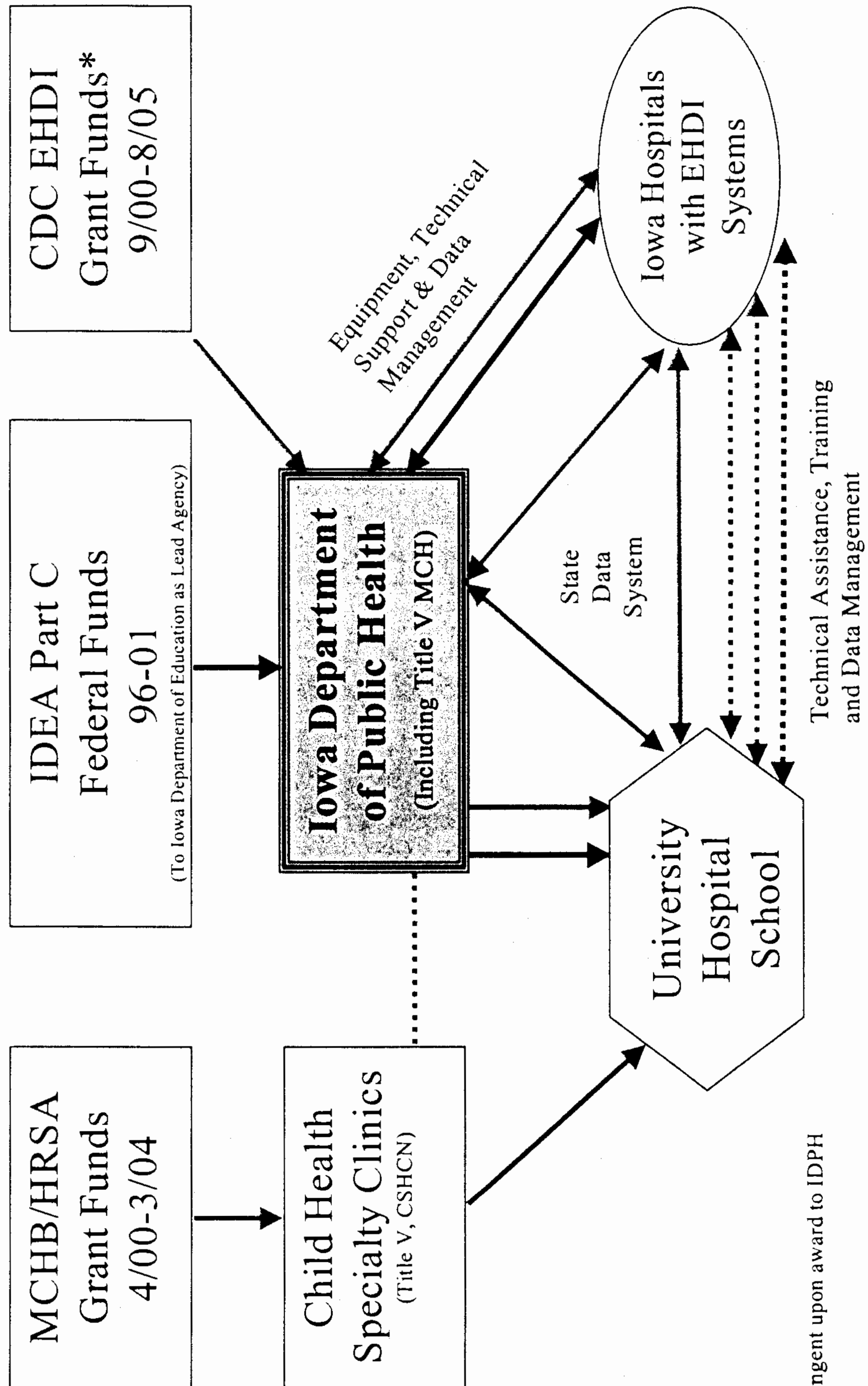
9.8 Capacity to coordinate grants - CHSC has a long history of partnership with MCHB in coordinating grants, including Healthy and Ready to Work, Iowa Medical Home Initiative, and States Systems Development grants.

9.9 Resources - Qualifications of staff are described in the Biographical Sketches of Key Personnel (Appendix C). Principal Investigator (Lobas), Project Director (Khal) and Project Coordinator (TBD), Senior Audiology Consultant (Holte) are housed in the CDD and have sufficient office space and computer capability to perform the activities of the proposed project.

The Audiology Consultants and EHDI Parent Consultant have sufficient computer capabilities to fulfill their contracted duties and to travel as required for networking and meeting coordination. Interagency resources will support training and planning for DHH mentors.

IDPH owns the license for the statewide surveillance system. The state uses eScreener Plus (eSP) web-based software and will provide user licenses for the CDD audiology consultants, AEA staff and OB hospital staff. eSP will allow for real-time reporting to the department and will be more accessible to users than the previous data system.

Child Health Specialty Clinics' financial officer will provide administrative oversight to assure that grant funds are used only for the purposes specified in this application.


IOWA EHDI SYSTEM FUNDING SOURCES & KEY
STAKEHOLDER DIAGRAM
MCHB/HRSA
Grant Funds
4/00-3/04
IDEA Part C
Federal Fund
96-01
(To Iowa Department of Education as Lead Agency)
CDC EHDI
Grant Funds*
9/00-8/05
Child Health
Specialty Clinics
(Title V, CSHCN)
Iowa Department
of Public Health
(Including Title V MCH)
Equipment, Technical
Support & Data
Management
Iowa Hospitals
with EHDI
Systems
State
Data
System
University
Hospital
School
Technical Assistance, Training
and Data Management
* Contingent upon award to IDPH
6-00

# Child Health Specialty Clinics

## Regional Centers

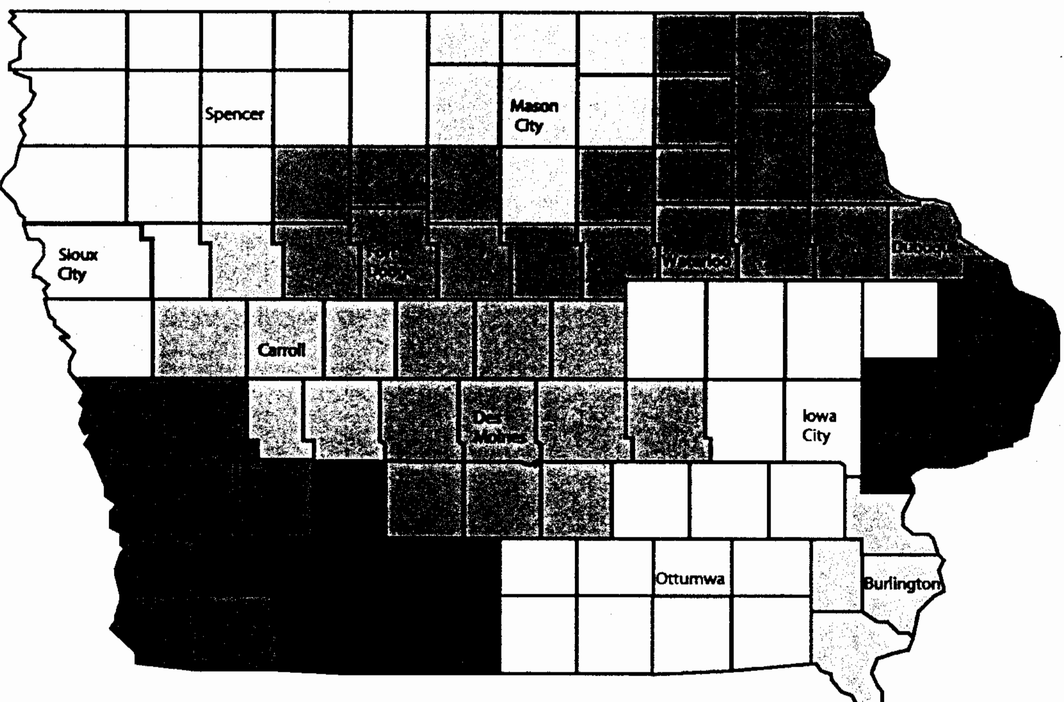
Burlington Regional Center
Child Health Specialty Clinics
Eastman Plaza
1223 S. Gear Avenue, Suite 012
West Burlington, IA 52655-1690
(319) 752-6313

Carroll Regional Center
Child Health Specialty Clinics
726 North Carroll, Suite 1
Carroll, IA 51401-2367
(712) 792-5530

Council Bluffs Regional Center
Child Health Specialty Clinics
3501 Harry Langdon Blvd., Suite 150
Council Bluffs, IA 51503-7894
(712) 309-0041
Toll Free: (866) 652-0041

Creston Regional Center
Child Health Specialty Clinics
1700 W. Townline St., Suite 2C
Creston, IA 50801-1054
(641) 782-3838
Toll Free: (866) 782-3838

Davenport Regional Center
Child Health Specialty Clinics
1401 West Central Park Avenue
Davenport, IA 52804-1769
(563) 421-2141




Waterloo Regional Center
Child Health Specialty Clinics
2101 Kimball Road, Suite 101
Waterloo, IA 50702-5057
(319) 272-2315

Spencer Regional Center
Child Health Specialty Clinics
1200 First Avenue East
Spencer, IA 51301-4330
(712) 264-6362
Toll Free: (877) 270-9386

Sioux City Regional Center
Child Health Specialty Clinics
St. Luke's Regional Medical Center
2720 Stone Park Boulevard
Sioux City, IA 51104-3795
(712) 279-3411
Toll Free: (800) 352-4660 ext. 3411

Ottumwa Regional Center
Child Health Specialty Clinics
317 Vanness Ave., Room 114
Ottumwa, IA 51501-1434
(641) 682-8145

Mason City Regional Center
Child Health Specialty Clinics
910 North Eisenhower Avenue
Mason City, IA 50401-1525
(641) 422-7388
Toll Free: (800) 433-3883 ext. 7388

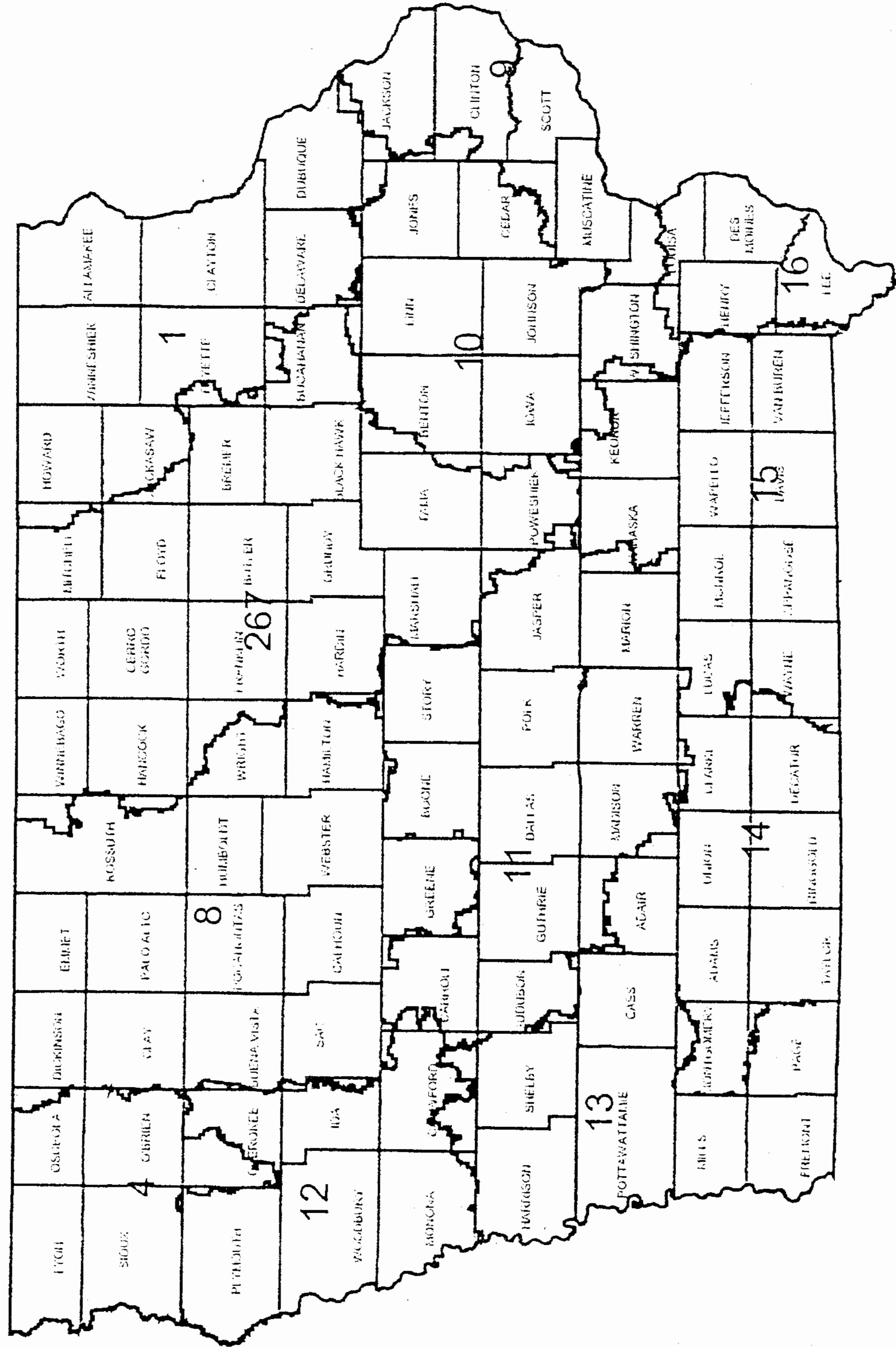
Des Moines Regional Center
Child Health Specialty Clinics
5406 Merle Hay Road
PO Box 707
Johnston, IA 50131-1269
(515) 727-4121
Toll Free: (866) 208-4088

Dubuque Regional Center
Child Health Specialty Clinics
2255 John F. Kennedy Road
Asbury Square, Lower Level
Dubuque, IA 52002-2846
(563) 588-0981
Toll Free: (888) 588-0981

Fort Dodge Regional Center
Child Health Specialty Clinics
Physicians Office Bldg. West
804 Kenyon Road Suite L
Fort Dodge, IA 50501-4901
(515) 955-8326

Iowa City Regional Center
(and administrative offices)
Child Health Specialty Clinics
100 Hawkins Drive, Room 247 CDD
Iowa City, IA 52242-1011
(319) 356-1117
Toll Free: (866) 219-9119

# Iowa Early ACCESS Regions



## Project Activities Time, Resources and Evaluation Table

Project Title: Iowa Newborn Hearing Screening and Intervention: Assuring Follow-Up
Principal Investigator: Jeffrey Lobas, M.D. - Project Director: Barbara Khal, M.A. – Project Coordinator: TBD - Budget Period: 4/1/05 to 3/31/08

| Objectives and Approaches and Timeframes | Grant Personnel | Other Resources/Collaborators | Tracking/Evaluation Methods |
|---|---|---|---|
| **G1: All newborns will be screened appropriately prior to hospital discharge.** | | | **Review of hospital screening data show benchmarks are being met.** |
| **Objective 1.1 – By March 31, 2008, reduce the percentage of missed screens to less than 1% of hospital births.** | | | **Percent of missed screens is less than 1% of hospital births, as reported by web-based hospital screening data.** |
| Activity 1.1.a - By March 31, 2006, develop newborn hearing screening protocols with endorsement from EHDI advisory committee and distribute protocols statewide to hospitals and audiologists. | Audiologists<br>Project Coordinator | EHDI Advisory Committee | Protocols developed and distributed according to timeline developed by Project Coordinator. |
| Activity 1.1.b – By March 31, 2007, ensure sustainability of loaner screening equipment program and publicize the availability of this program. | Project Coordinator<br>Audiologists | Financial support from grant. Hospital staff and stakeholder groups. | Loaner units purchased. Publications distributed |
| Activity 1.1.c – Continually monitor hospital reports to determine which hospitals are missing hearing screenings at the birth admission and why. | Project Coordinator<br>Audiologists | IDPH CDC Data personnel | Data reports produce periodic data that allows for targeting technical assistance. |
| **Objective 1.2 – By March 31, 2008, reduce hospital refer rates to less than 8% in the well-baby nursery.** | | | **Hospital refer rates are less than 8% in the well baby nursery, as reported by web-based hospital screening data.** |
| Activity 1.2.a – Create data reports on ongoing basis to monitor hospital refer rates. | Project Coordinator | IDPH State EHDI Coordinator | Data reports are printed on schedule and results monitored. |
| Activity 1.2.b – Offer technical assistance to hospitals with refer rates higher than 8%. | Audiologists | IDPH State EHDI Coordinator | TA is received by hospitals with refer rates higher than 8%, within one month of report identifying need. |
| Activity 1.2.c – Educate hospital staff about reducing refer rates by submitting articles to the state EHDI newsletter on a semi-annual basis. | Project Coordinator | IDPH State EHDI Coordinator<br>Part C Technical Consultants | Articles appear in state newsletter semi-annually. |
| **G2: All audiologic diagnoses will occur before children are 3 months of age.** | | | **Monitoring of Part C data indicate diagnoses did occur by age 3 mo.** |

## Project Activities Time, Resources and Evaluation Table

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| Objectives and Approaches and Timeframes | Grant Personnel | Other Resources/Collaborators | Tracking/Evaluation Methods |
|---|---|---|---|
| **Objective 2.1 – By March 31, 2006, develop communication tools for hospitals to use to communicate screening results to parents.** | | | **Communication tools are created and field-tested within timeframe.** |
| Activity 2.1.a – Revise standard letters available in EHDI data system to assure health literacy level and appropriateness. | Project Coordinator<br>EHDI Parent Consultant | EHDI Advisory Committee<br>IDPH Health Literacy Team<br>IDPH State EHDI Coordinator | Consultation by experts within CDC and field tests confirm appropriateness. |
| Activity 2.1.b - Translate standard letters available in EHDI data system into additional languages as requested by hospitals and audiologists. | Project Coordinator<br>Audiologists | Translator | Field tested by appropriate minority parents. Monitor for additional language needs on ongoing basis. |
| Activity 2.1.c - Develop, distribute and analyze a survey to determine parents' perceptions about the communication they received about the newborn hearing screening from the hospital and use the survey analysis to guide technical assistance to hospitals. | EHDI Parent Consultant<br>Project Director<br>Project Coordinator | EHDI Advisory Committee<br>Other state parent groups | Survey is completed within timeframe and results are used beginning April 2006 for program revisions, if indicated. |
| **Objective 2.2 - By March 31, 2008 increase AEA provider knowledge of Part C (Early ACCESS) EHDI procedures and Best Practice guidelines.** | | | **Monitoring review by State Coordinator of Teachers of Deaf or Hard of Hearing and Part C TA reveals provider knowledge and competency** |
| Activity 2.2.a - Provide training to each AEA region regarding Part C (Early ACCESS) EHDI procedures and Best Practice Guidelines. | Project Coordinator | IDPH Part C Technical Consultant<br>IDPH State EHDI Coordinator | Training schedule indicates that each region has received training. |
| Activity 2.2.b - Review Early ACCESS regions' EHDI procedures and provide technical assistance to regions whose procedures are not adequate. | Project Coordinator | IDPH Part C Technical Consultant<br>IDPH State EHDI Coordinator | All Early ACCESS regions have approved EHDI procedures. |
| Activity 2.2.c - Monitor data regarding age of diagnosis and entry into early intervention and provide technical assistance to AEAs as necessary. | Project Coordinator | IDPH Part C Technical Consultant<br>IDPH State EHDI Coordinator | Reports created, printed and analyzed on schedule. |
| **G3: All eligible children will be enrolled in an early intervention program (Part C, Early ACCESS) before 6** | | | **Part C monitoring data report children are enrolled prior to 6** |

## Project Activities Time, Resources and Evaluation Table

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Principal Investigator: Jeffrey Lobas, M.D. - Project Director: Barbara Khal, M.A. – Project Coordinator: TBD - Budget Period: 4/1/05 to 3/31/08

| Objectives and Approaches and Timeframes | Grant Personnel | Other Resources/Collaborators | Tracking/Evaluation Methods |
|---|---|---|---|
| **months of age.** | | | **months of age.** |
| **Objective 3.1 – By April 1, 2006, establish data sharing procedures between EHDI and Early ACCESS.** | | | **Data sharing procedures between EHDI and Early ACCESS are in place.** |
| Activity 3.1.a – Collaborate with CDC systems development grant efforts for web-based reporting, and provide financial support for site licensing requirements. | Project Coordinator | IDPH State EHDI Coordinator<br>IDPH Part C Technical Consultant | User licenses are secured and collaboration with CDC grant staff is occurring. |
| **Objective 3.2 – By April 1, 2007, assure that infants with congenital hearing loss will have access to appropriate early intervention services.** | | | **Part C monitoring data indicate that 100% of infants with congenital hearing loss identified by hospital screening data, have access to appropriate early intervention services.** |
| Activity 3.2.a – Assure infants with congenital hearing loss are referred to appropriate services for fitting for amplification by 6 months of age. | Project Coordinator | IDPH State EHDI Coordinator<br>Contract audiologists | EHDI data reports showing age at fitting for amplification are developed and analyzed. |
| Activity 3.2.b - Educate potential referral sources about Early ACCESS referral procedures. | Project Coordinator<br>Project Director | Early ACCSESS Regional Liaisons<br>IDPH Part C Technical Consultant | |
| Activity 3.2.c - Inform members of the Iowa Council for Early ACCESS, the EHDI Advisory Committee and the Title V grantee agencies of the Early ACCESS referral procedures. | Project Coordinator<br>Project Director | IDPH Part C Technical Consultant<br>IDPH State EHDI Coordinator | Meeting minutes and/or correspondence show discussion of referral procedures |
| Activity 3.2.d - Early ACCESS regional grantees will inform their regional councils of Early ACCESS referral procedures. | Project Coordinator<br>Project Director | Early ACCSES Regional Liaisons<br>IDPH Part C Technical Consultant | Meeting minutes and/or correspondence show Early ACCESS Regional Liaisons were asked to discuss referral procedures with their Regional Councils. |
| Activity 3.2.e - Include information about Early ACCESS referral procedures in letters to physicians regarding infants' | Project Coordinator | IDPH State EHDI Coordinator | All letters include Early ACCESS referral procedures |

## Project Activities Time, Resources and Evaluation Table

Project Title: Iowa Newborn Hearing Screening and Intervention: Assuring Follow-Up
Principal Investigator: Jeffrey Lobas, M.D. - Project Director: Barbara Khal, M.A. – Project Coordinator: TBD - Budget Period: 4/1/05 to 3/31/08

| Objectives and Approaches and Timeframes | Grant Personnel | Other Resources/Collaborators | Tracking/Evaluation Methods |
|---|---|---|---|
| hearing screening/diagnostic results. | | | |
| **G4: All families with children 0-3 who are deaf or hard of hearing or are at risk for late-onset hearing loss will be linked to a medical home.** | | | **Random review of data of at-risk children indicates all linked to a medical home.** |
| **Objective 4.1 – By March 31, 2008, establish a system to regularly monitor infants who pass the newborn hearing screening, but are at risk for late-onset hearing loss.** | | | **System is developed within timeframe.** |
| Activity 4.1.a – By March 1, 2007, develop statewide protocols to provide periodic audiologic monitoring for infants at risk for late onset hearing loss, using the latest recommendations of the Joint Committee on Infant Hearing (JCIH) as a guide and obtain EHDI advisory committee endorsement for these protocols. | Audiologists<br>CHSC - PNP | CHSC Regional Centers<br>Iowa Medical Home Initiative<br>IDPH EHDI Coordinator<br>Part C | Protocols are developed within timeframe. |
| Activity 4.1.b – By July 31, 2007, partner with Iowa's AAP Chapter Champion, the Iowa Academy of Family Physicians, the Iowa Academy of Otolaryngology, AEA administrators, and Iowa's Title V program for children with special health care needs to disseminate monitoring protocols to their constituent groups. | Project Coordinator<br>Project Director<br>Part C Tech Cons.<br>CHSC - PNP | American Academy of Pediatrics<br>Iowa Medical Home Initiative<br>IA Academy of Family Physic<br>Area Education Agencies<br>IA Academy of Otolaryngology<br>Iowa Title V/CHSC | Protocols are disseminated to all groups and staff is trained as needed. |
| Activity 4.1.c – By July 31, 2007 present monitoring protocols to the Iowa Perinatal Conference and other meetings of providers of medical care to infants and toddlers. | Project Coordinator | IDPH EHDI Coordinator<br>Contract Audiologists<br>IDPH Perinatal Consultant | Training occurs at Iowa Perinatal Conference. |
| **Objective 4.2 – By March 31, 2007, develop best medical practices guidelines for Iowa's primary care physicians, using materials provided by Iowa's AAP chapter champion.** | | | **Best practice guidelines are developed according to AAP standards within timeframe.** |
| Activity 4.2.a - Obtain EHDI advisory committee endorsement of the best practices guidelines. | Project Coordinator | EHDI Advisory Committee | |
| Activity 4.2.b - Disseminate the guidelines to physicians and train them to implement these practices at annual meetings of the Iowa Academy of Pediatrics and Iowa Academy of | Principal Investigator<br>Project Coordinator | Iowa Medical Home Initiative<br>AAP Chapter Champion<br>IAFP | Training occurs at annual meetings within timeframes. |

## Project Activities Time, Resources and Evaluation Table

Project Title: Iowa Newborn Hearing Screening and Intervention: Assuring Follow-Up
Principal Investigator: Jeffrey Lobas, M.D. - Project Director: Barbara Khal, M.A. – Project Coordinator: TBD - Budget Period: 4/1/05 to 3/31/08

| Objectives and Approaches and Timeframes | Grant Personnel | Other Resources/Collaborators | Tracking/Evaluation Methods |
|---|---|---|---|
| Family Physicians | | | |
| **Objective 4.3 – By April 1, 2007, inform EPSDT care coordinators of EHDI issues.** | | | **EPSDT care coordinators are informed of EHDI issues.** |
| Activity 4.3.a - Present EHDI procedures and resources at EPSDT Conference. | Project Coordinator | IDPH State EHDI Coordinator<br>IDPH EPSDT Team | Training will be provided at State EPSDT Conference. |
| Activity 4.3.b - Submit article regarding EHDI procedures and resources to EPSDT newsletter. | Project Coordinator | IDPH State EHDI Coordinator<br>IDPH EPSDT Team | EHDI article will be published in EPSDT newsletter. |
| **Objective 4.4 – By April 1, 2006, develop a plan for linkage with other early childhood system initiatives.** | | | **Other early childhood initiatives in Iowa will reflect collaboration with EHDI project** |
| Activity 4.4.a - Collaborate with the Early Childhood Iowa Stakeholders and the Quality Services and Programs workgroup to ensure that EHDI issues are integrated into the Early Child Health and Education System | Project Coordinator | IDPH State EHDI Coordinator<br>IDPH Early Childhood Comprehensive Systems Coordinator | EHDI issues will be integrated into the Early Child Health and Education System |
| Activity 4.4.b - Collaborate with the Department of Education and Department of Human Services to integrate protocols and procedures for children who are deaf and hard of hearing into the Early Learning Standards for children aged 0-3 in physical, social and emotional domains. | Project Coordinator | IDPH State EHDI Coordinator<br>IDPH Early Childhood Comprehensive Systems Coordinator | Protocols and procedures for children who are deaf and hard of hearing will be integrated into Early Learning Standards for children 0-3. |
| Activity 4.4.c - Provide updated information about EHDI to local Community Empowerment board members through newsletters and meetings. | Project Coordinator | IDPH Representative to the State Empowerment Team | EHDI articles will be published in the Empowerment newsletter and meeting minutes will reflect discussion of EHDI issues. |
| Activity 4.4.d - Partner with the Iowa Medical Home Initiative to provide training to medical home partner clinics' staff | Principal Investigator<br>Project Coordinator | Iowa Medical Home Initiative | Medical home partner clinics' staff receive training within timeframe. |
| **G5: All families with children 0-3 who are deaf or hard of hearing will receive family-to-family support.** | | | **Part C monitoring benchmarks regarding family support are met.** |
| **Objective 5.1 – By April 1, 2007, assure parents of Iowa's deaf and hard-of-hearing children will have access to ongoing support through family organizations.** | | | **Survey of parents of deaf or hard of hearing children indicate their knowledge of and access to family organizations.** |