

Iowa's Title V Program for Children with Special Health Care Needs

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October 29, 2004

Regional Centers

Burlington

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Council Bluffs

Creston

Davenport

Des Moines

Dubuque

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Spencer

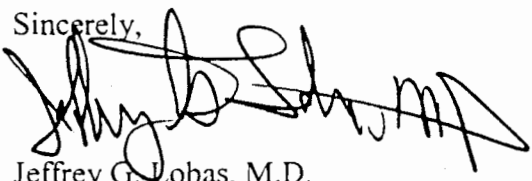
Waterloo

HRSA Grants Application Center
The Legin Group, Inc.
Attn: Universal Newborn Hearing Screening and Intervention
Program Announcement No., HRSA 05-090, CFDA No. 93-251
901 Russell Avenue, Suite 450
Gaithersburg, MD 20879

RE: Program Title: Universal Newborn Hearing Screening and Intervention
(Priority I)
Program #: CFDA #93.251 – HRSA-05-090

Child Health Specialty Clinics is pleased to have the opportunity to apply for federal funds to improve the follow-up of infants who are deaf or hard of hearing. Enclosed please find the application for the proposal titled: *Iowa Newborn Hearing Screening and Intervention – Assuring Follow-up.*

Thank you for considering our application.

Sincerely,


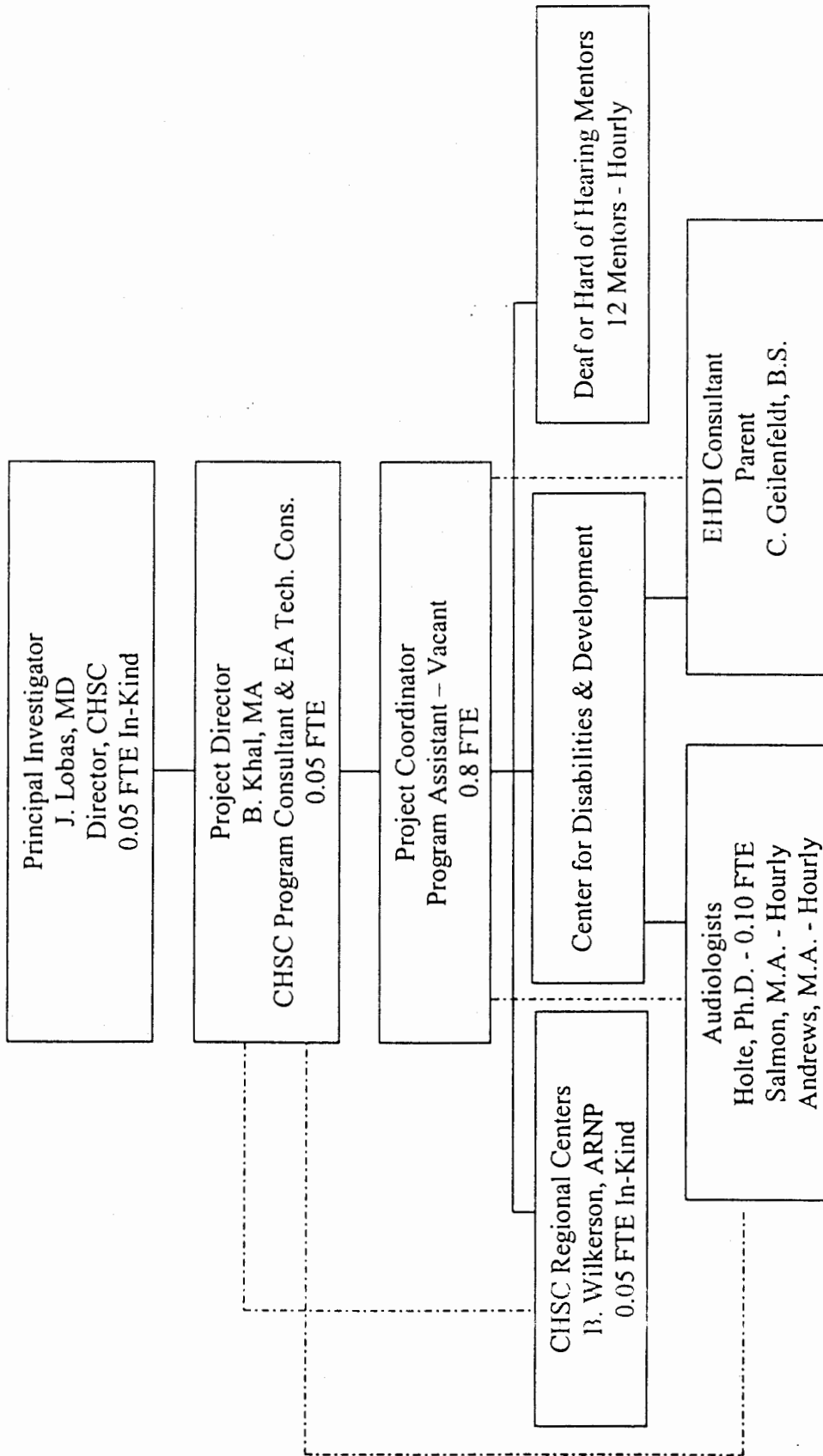
Jeffrey G. Lobas, M.D.
Director

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**Early Hearing Detection & Intervention
Staffing Plan - Key Personnel
Program Outline**



Position Descriptions with Roles and Responsibilities and Qualifications are included in Appendix B
Biographical Sketches of Key Personnel are included in Appendix C.

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.

Relationship to Healthy People 2010

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 hard 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 responsibilities 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.

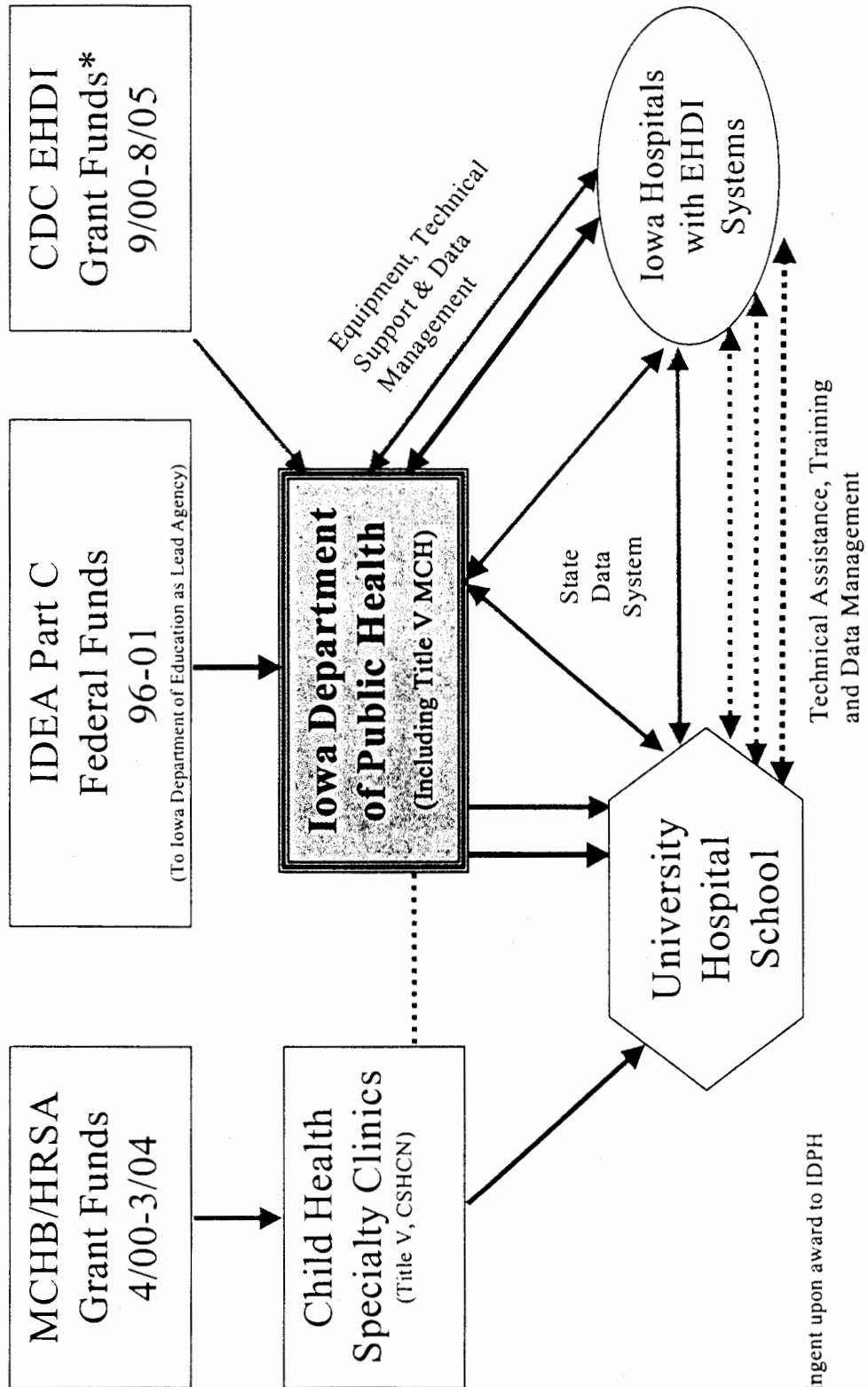
9.9 Resources - Qualifications of staff are described in the Biographical Sketches of Key Personnel (Appendix C). Principal Investigator (Lobas), Project Director (Khal) and Project Coordinator (TBD), Senior Audiology Consultant (Holte) are housed in the CDD and have sufficient office space and computer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



* Contingent upon award to IDPH

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

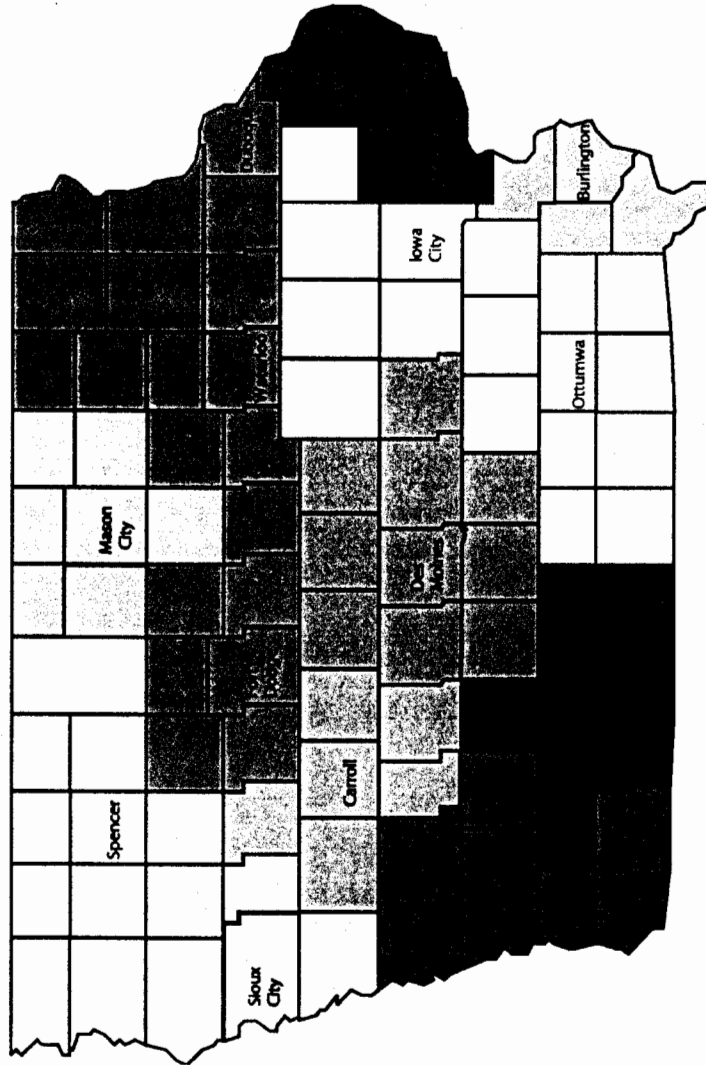
Carroll Regional Center
 Child Health Specialty Clinics
 726 North Carroll, Suite 1
 Carroll, IA 51401-2367
 (712) 792-5530

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

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



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

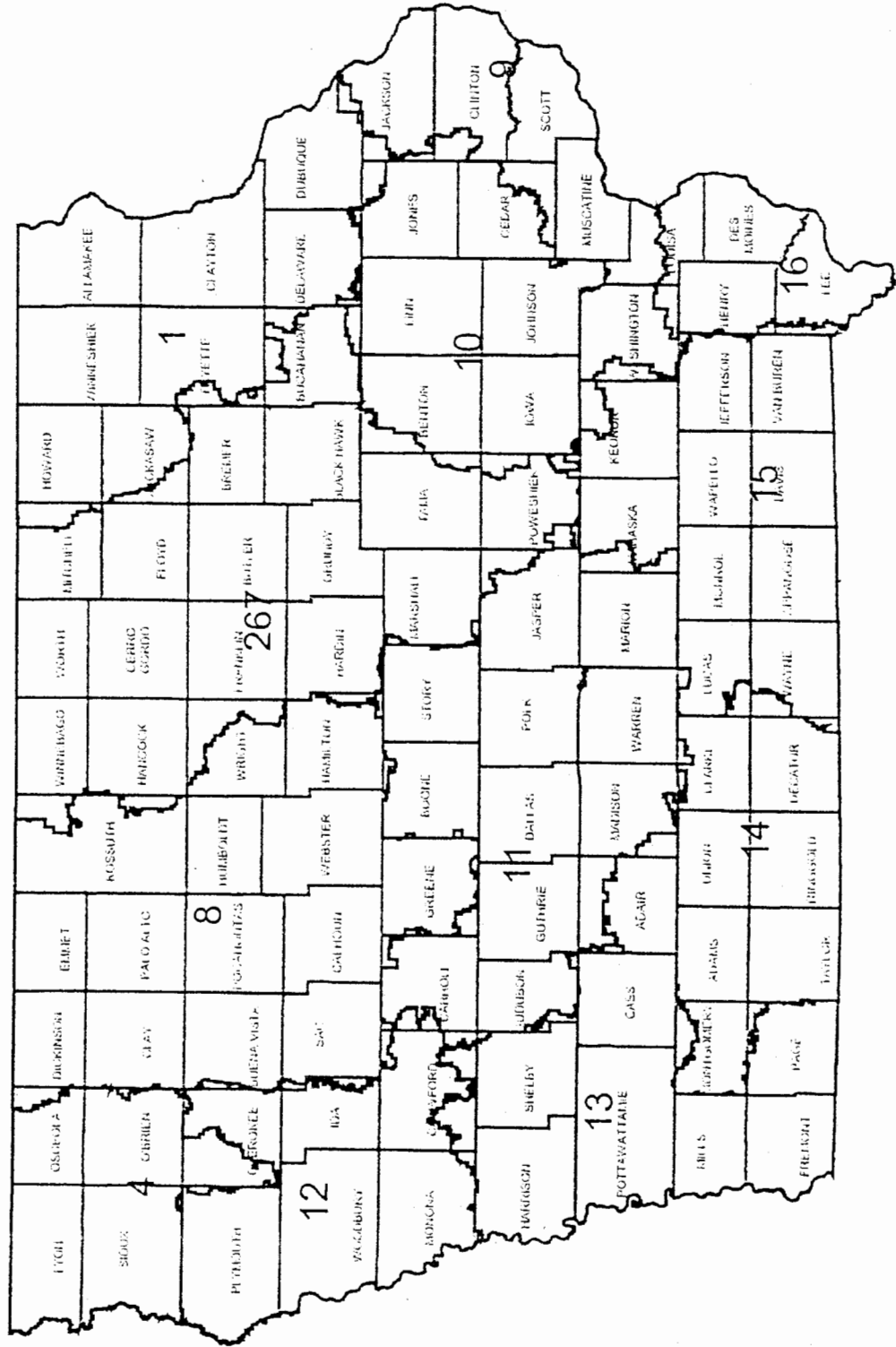
Mason City Regional Center
 Child Health Specialty Clinics
 910 North Eisenhower Avenue
 Mason City, IA 50401-1525
 (641) 422-7388
 Toll Free: (800) 433-3883 ext. 7388

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

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

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

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 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 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 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 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

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
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 EHDI Parent Consultant	EHDI Advisory Committee IDPH Health Literacy Team 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 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 Project Director Project Coordinator	EHDI Advisory Committee 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 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 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 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

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
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 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 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 Project Director	Early ACCESS Regional Liaisons 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 Project Director	IDPH Part C Technical Consultant 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 Project Director	Early ACCSES Regional Liaisons 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 CHSC - PNP	CHSC Regional Centers Iowa Medical Home Initiative IDPH EHDI Coordinator 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 Project Director Part C Tech Cons. CHSC - PNP	American Academy of Pediatrics Iowa Medical Home Initiative IA Academy of Family Physic Area Education Agencies IA Academy of Otolaryngology 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 Contract Audiologists 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 Project Coordinator	Iowa Medical Home Initiative AAP Chapter Champion 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 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 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 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 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 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.

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
Activity 5.1.a - Partner with the Iowa chapter of Hands and Voices to provide a parent consultant to the EHDI system	Project Coordinator EHDI Parent Cons.r	CHSC Parent Consultants, Part C Parents as Presenters	Parent Consultant is hired and networked other parent groups and networks.
Activity 5.1.b - Train advocates with the Iowa Chapter of Hands and Voices on appropriate family support.	Project Coordinator and Part C TA	Part C Technical Consultants State Coordinator of Children who are Deaf or Hard of Hearing	Parents have completed Part C training modules and exhibits skills of family-centered practices.
Activity 5.1.c - Collaborate with CHSC, Early ACCESS parent consultants, Parent Educator Connection, Family Voices, and other groups to ensure that parents are informed about services offered by Hands and Voices	Project Director Project Coordinator	CHSC Parent Consultants Part C Parents and Presenters ASK Resource Center	Interviews indicate parent groups within the state are knowledgeable of Hands and Voices.
Activity 5.1.d - Work with Iowa Deaf and Hard of Hearing Summit conference planners to assure that EHDI issues are addressed.	Project Coordinator EHDI Parent Consultant	In-kind support for co-sponsoring agencies.	EHDI Issues will be addressed at Iowa Deaf and Hard of Hearing Summit.
Objective 5.2 - By March 31, 2008, develop and implement a Deaf and Hard of Hearing Mentoring program.			Parents of newly identified deaf or hard of hearing children are connected to DHH mentors and receive appropriate services.
Activity 5.2.a - By March 31, 2006, plan, inform stakeholders, recruit and select DHH Mentors.	Project Coordinator	State Consultant to Deaf and HOH; Area Education Agencies; EHDI Advisory Group	DHH mentors will be hired and trained within timeframe.
Activity 5.2.b - From April 1, 2006 through March 31, 2008, connect families with DHH mentors.	Project Coordinator	Part C regional liaisons and service coordinators. Part B funds to help support. Iowa School for the Deaf	Part C monitoring data shows children are receiving DHH mentor services.
Appendix G - Tables and Forms	In addition to the evaluation and monitoring activities in this chart, data will be collected and reported annually for all federally required tables and forms.		

Position Descriptions with Roles and Responsibilities

Position Description: Principal Investigator – 0.05 FTE In-Kind**Jeffrey G. Lobas, M.D., MPA****Director, Child Health Specialty Clinics****Professor, Dept. of Pediatrics, The University of Iowa**

Administrative Direction: Dr. Lobas will provide overall program direction for the entire grant process.

Functional Relationships: Dr. Lobas is Professor of Clinical Pediatrics at The University of Iowa and holds a clinical appointment at The University of Iowa Hospitals and Clinics. His office is located at the Center for Disabilities and Development (CDD), which also houses Iowa's University Center for Excellence in Disabilities (UCED). He directs Child Health Specialty Clinics (CHSC), Iowa's Title V program for children with special health care needs. CHSC is one of the four signatory parties of the Early ACCESS statewide interagency system of early intervention, and as such Dr. Lobas confers regularly with leadership from the Iowa Departments of Public Health, Education, and Human Services. He is also a member of the Iowa Maternal and Child Health Advisory Council, an advisory council for the State's Title V programs comprised of representatives from public, private and voluntary organizations concerned with the health and health-related issues of Iowa's children and families. Dr. Lobas is principle investigator for the Iowa Medical Home Project and President-Elect of the National Association of Maternal Child Health Programs.

Roles/Responsibilities:

1. Provide vision, leadership, and oversight to entire grant process
2. Be the liaison for resources from Child Health Specialty Clinics, Early ACCESS Executive Committee, the Iowa Medical Home Project, and the American Academy of Pediatrics

Qualifications: Director of Title V CHSC Program; Pediatrician

Position Description: Project Director – 0.05 FTE**Barbara Khal, MA****Child Health Specialty Clinics and Part C Technical Consultation**

Administrative Direction: Barbara Khal will provide administrative direction to the Project Coordinator.

Functional Relationships: Barbara Khal will report to the Director of Child Health Specialty Clinics. She will be a liaison for the Early ACCESS Technical Assistance Team, CDD audiologists and the CHSC Regional Health Service Coordinator.

Roles/Responsibilities:

1. Provide vision and leadership to grant process and supervise the Project Coordinator
2. Be a liaison between CHSC, Early Hearing Detection and Intervention (EHDI), Early ACCESS Technical Consultant Team, and audiologists
3. Represent CHSC on Newborn Hearing Screening Advisory Committee

Qualifications: Master's degree plus at least five years experience working in the public health.

**Position Description: Project Coordinator – to be determined – 0.80 FTE
Child Health Specialty Clinics**

Administrative Direction: Project coordinator will provide administrative direction to the Deaf and Hard of Hearing Mentors and EHDI parent consultant. S/He will consult with Senior Audiologist regarding targeted technical consultant needs, Part C Technical Consultants, and CHSC Regional Health Services Coordinators.

Functional Relationships: Project Coordinator will report to the Project Director.

Roles/Responsibilities:

1. Communicate with hospital personnel regarding screening programs, data management, and training
2. Supervise management of state database of newborn hearing and screening results
3. Prepare publications regarding Iowa's newborn hearing screening program
4. Prepare progress reports to Maternal and Child Health Bureau
5. Prepare parent informational materials with collaboration of EHDI parent consultant
6. Communicate with Perinatal Review Team regarding screening programs in perinatal programs they review
7. Speak to groups of physicians, nurses, parents, educators, early interventionists and audiologists regarding newborn hearing screening program
8. Work with webmaster to provide informational materials to families and professionals on website
9. Facilitate Newborn Hearing Screening Advisory Committee with CDCC State EHDI Data Management Coordinator
10. Coordinate Family Conference/Deaf and Hard of Hearing Summit with other participating agencies
11. Provide training to program managers regarding data management
12. Arrange for internal and external interagency meetings and conferences
13. Collect and compile data, preparing as periodic reports for grant funding sources
14. Conducts surveys and compiles and analyzes the information obtained
15. Tracks federal and state legislation relevant to newborn hearing screening
16. Prepare grant applications including conducting research, compiling data, drafting sections, and editing applications
17. Establish and maintain grant financial records, review grant expenditures and reconcile grant accounts

Qualifications: Program Assistant. Bachelor's degree or equivalent combination of education and experience. 6 months-1 year related administrative and program experience. Flexible schedule and travel required.

**Position Description: Senior Audiologist Consultant 0.10 FTE
Lenore Holte, PhD.
Center for Disabilities and Development**

Administrative Direction: Dr. Holte will provide technical expertise for the audiologic components of the project and oversight to audiological quality control consultants.

Functional Relationships: Dr. Holte will consult with the Project Director and Project Coordinator. In all matters regarding University Center for Excellence in Disabilities (UCED) projects she reports to the UCED Director and the Center for Disabilities and Development.

Roles/Responsibilities:

1. Plan and supervise quality control activities of consultants
2. Provide technical assistance as required
3. Coordinate continuing education workshops for audiologists
4. Coordinate audiology graduate student training activities with newborn hearing screening program
5. Author Best Practice Protocols
6. Report quality control data to Project Director and Project Coordinator

Qualifications: Ph.D. in Audiology

**Position Description: Quality Control Audiology Consultant – 0.20 FTE per audiologist
Nick Salmon, M.A. and Emily Andrews, M.A.**

Administrative Direction: No administrative responsibilities.

Functional Relationships: Each consultant will provide targeted training to screening in hospitals with unacceptable refer rates and report to the Senior Audiology Consultant, Dr. Holte, at CDD.

Roles/Responsibilities:

1. Provide training and technical assistance to screeners of newborn hearing
2. Report quality control indicators to senior audiology consultant
3. Participate in preparation of continuing education for audiologists
4. Supervise graduate students in audiology in newborn hearing screening experiences

Qualifications: Master's degree in audiology with a minimum of two years of experience in pediatric audiology, including newborn hearing screening program management.

**Position Description: EHDI Parent Consultant - One day per week
Cami Geilenfelt-**

Administrative Direction: No administrative responsibilities

Functional Relationships: Will report to Project Coordinator

Roles/Responsibilities:

1. Implement the family support goals of Iowa's Early Hearing Detection and Intervention project
2. Coordinate the activities of the Iowa EDHI advisory committee and the Iowa Chapter of Hands and Voices
3. Manage the development of the Iowa Hands and Voices chapter
4. Network with other statewide parent groups regarding EHDI
5. Participate in grant writing to sustain the Iowa EDHI program

Qualifications: Parent of a child who is deaf or hard of hearing, who has been trained by State Coordinator for Teacher of Deaf or Hard or Hearing and Early ACCESS state staff regarding family-centered practices and EHDI.

Position Description: Deaf or Hard of Hearing Mentors – to be determined
One Deaf or HOH mentor will be available as needed in each Early ACCESS region –
Hourly Wages @ \$15/hr. – Estimated time allocated for each of 12 regions is 125 hours.

Administrative Direction: No administrative responsibilities

Functional Relationships: Will report to Project Coordinator

Roles/Responsibilities:

1. Offer support as the family develops their understanding of their child's deafness or hearing loss
2. Share personal experiences as they relate to the family's situation
3. Provide a language model in the communication modes chosen by the family
4. Provide information on the local deaf or hard of hearing community
5. Be a resource for assistive technology
6. Provide parents with opportunities to identify their child's subtle communication attempts and to evaluate their child's strengths in communicating
7. Increase parent's appreciation for and understanding of American Sign Language (ASL), Deaf Culture, and the Deaf Community
8. Support the child's development of language, communication, and self-identity through use of American Sign Language and the child's ability to interact with a Deaf or Hard of Hearing adult role model

Qualifications: Adult who is deaf or hard of hearing who has been trained by Department of Education's State Coordinator for Teachers of Deaf or Hard of Hearing

Position Description: Regional Health Services Coordinator - 0.05 FTE In-Kind
Barbara Wilkerson, ARNP

Administrative Direction: None

Functional Relationships: Collaborates with Principal Investigator, Project Director and Project Coordinator

Roles/Responsibilities:

1. Provide direction and implementation oversight to CHSC Health Services Coordinators in fourteen regional centers re protocols to monitor children at-risk for late on set hearing loss
2. Link CHSC Parent Consultant Network with EHDI parent consultants, deaf mentors and Hands and Voices members

Qualifications: Pediatric Nurse Practitioner

BIOGRAPHICAL SKETCH

Name: Lobas, Jeffrey George

Title on Training Grant: Co-Director

Education:

Institute and Location	Degree	Year(s)	Field of Study
Purdue University	B.S.	1972	
The Ohio State University	M.P.A.	1974	Public Administration
Medical College of Ohio	M.D.	1979	
University of Oregon		1979-80	Internship in Pediatrics
Medical College of Ohio		1980-81	Internship in Internal Medicine
Medical College of Ohio		1981-82	Resident in Peds & Int. Med
Medical College of Ohio		1982-83	Chief Resident in Pediatrics
University of Wisconsin		1983-86	Fellowship/Ped. Pulmonology and Ped. Critical Care
University of St. Thomas		2000- present	Doctorate in Organization Development

Professional Experience:

2002-Present Professor of Clinical Pediatrics, University of Iowa
 Co-Director Iowa Leadership Education in Neurodevelopmental Disabilities Project
 1997-Present Director, Child Health Specialty Clinics, Iowa City, IA
 1997-2002 Associate Professor of Clinical Pediatrics, University of Iowa
 1995-97 Chair, Departmental Quality Improvement Program, Hennepin County Medical Center
 1994-97 Director of Pediatric Inpatient Services and of Pediatric Critical Care, Hennepin County Medical Center, Minneapolis, MN
 1994-97 Assistant Professor of Pediatrics, University of Minnesota
 1988-93 Managing Business Partner, Children's Respiratory and Critical Care Specialists, PA, Minneapolis Children's Medical Center, Minneapolis, MN
 1987-94 Clinical Assistant Professor of Pediatrics, University of Minnesota
 1986-87 Assistant Professor of Pediatrics, Indiana University
 1974-76 Health Planner Analyst, Columbus Health Department, Columbus, OH
 1973-74 Administrative Analyst, Columbus Health Department, Columbus, OH

Selected Appointments and Professional Memberships

2003-present President-elect, Association of Maternal and Child Health Program
 2002-present Trustee, Iowa Chapter of the American Academy of Pediatrics
 2002 Member, Expert Panel for Maternal and Child Health Bureau/Association of Maternal and Child Health Programs Early Childhood States System Development Initiatives to Develop Recommendations and Action Plan
 2002 Grant Reviewer, Health Resources and Services Administration: Healthy and Ready to Work
 2001-present Member, Health Systems Research National Policy Center for Children with Special Health Care Needs Advisory Committee

- 2001-present Co-Chair, Association of Maternal and Child Health Programs Policy and Program Committee
- 2001-present Member, National Center for Cultural Competence Advisory Committee for the Children with Special Health Care Needs
- 2001 Grant Reviewer, Department of Health & Human Services-Health Resources and Services Administration-Maternal and Child Health Bureau, Healthy and Ready to Work
- 2000-present Member, Health Systems Research Expert Panel for Children with Special Health Care Needs—Coordination of Mental and Physical Health Services
- 2000 Member, Expert Panel for Addressing Adolescent Transitioning, Agency for Healthcare Research and Quality (AHRQ)
- 1999-present Member, Early Access Council for Children and Families and Management Team for the Early Access Program
- 1999-present Member, HAWK-I Quality Assurance Committee
- 1999 Member, Expert Panel to Develop a Standard Definition for Children with Special Health Care Needs, Maternal and Health Bureau
- 1998-present Chair, HAWK-I Subcommittee for Children With Special Health Care Needs
- 1998-present Member, Healthy Iowans 2010
- 1997-present Member, State Maternal and Child Health Advisory Council

Honors and Awards:

- 2002 Healthcare Foundation of New Jersey and Arnold P. Gold Foundation Humanism in Medicine Award at the University of Iowa Roy and Lucille Carver College of Medicine
- 2001 Pediatric Resident's Award for Outstanding Resident Advocacy, University of Iowa
- 1996 Outstanding Faculty Educator Award, Department of Pediatrics, University of Minnesota
- 1996 George R. Noren Pediatric Faculty Teaching Award for 1995-96, University of Minnesota
- 1979 Upjohn Award, Medical Student Achievement Award, Medical College of Ohio

Selected Peer-reviewed Publications

1. Lobas JG, et al. (2000). Genetic analysis of sin nombre hantavirus in Iowa. *Pediatrics Infectious Disease Journal*. 19:355-358, No. 4.
2. Allen D, Bronheim SM, Bruder MB, Buchanan g, Clark G, De Carolis G, Gallagher J, Hess CA, Ireys HT, Kagan JB, Kohrt A, Kus C, Lobas JG, McPherson MG, Peterson E, Presler B, Roberts R, Robinson C, Sloyer P, Stettner-Eaton B, Weissman G, Wells C, Wells N. (2000). Care coordination for children with special health care needs and their families in the new millennium. *Association of Maternal and Child Health Program*.
3. Lobas JG. (1999). *Healthy and well kids in Iowa (HAWK-I) children with special health care needs subcommittee report to the HAWK-I board and State of Iowa legislators*.
4. Wheeler WB, Maguire E, Lobas JG, Fugate J, McNamara J. (1994). Chronic respiratory failure of infancy and childhood. Clinical outcomes based on underlying etiology. *Pediatric Pulmonology*. 17:1-5.
5. Wheeler WB, Kuracheck SC, Lobas JG, Lipscomb TS. (1991). Respiratory complications of tracheocutaneous fistula closure. *Critical Care Medicine*. 19:580-582.

BIOGRAPHICAL SKETCH

Name: Khal, Barbara J.

Education:

Institution and Location	Degree	Year(s)	Field of Study
University of Iowa, Iowa City, IA	B.S.	1972	Special Education
University of Iowa; Iowa City, IA	M.A.	1998	Instructional Design and Technology

Professional Experience:

1987-Present Child Health Specialty Clinics
 2002-Present Training Director, Iowa Leadership Education in Neurodevelopmental Disabilities Project
 2002-Present Director, Creston Behavioral Health Program Pilot Project
 2002-Present Magellan Telehealth Project
 2001-Present Program Consultant and Co-Director Policy and Planning Unit
 1996-Present Technical Consultant/CHSC Liaison to Early ACCESS (Part C)
 1999-2001 Co-principal Investigator for State Systems Development Grant: Iowa Children and Families: A Household Health Survey
 1996-2001 Iowa Child Development Coordinating Council
 1996-2000 Program Associate, Child Health Specialty Clinics
 1994-2000 Co-Chair Annual Iowa Maternal and Child Health Conferences
 1992-1996 Community ACCESS to Child Health Projects (CATCH/American Academy of Pediatrics)
 1992-2000 Director, Children with Special Health Care Needs Child Care Inclusion Project
 1992-1996 Early Care and Education State Advisory Group
 1992-1995 Program Assistant, Child Health Specialty Clinics
 1987-1991 Executive Secretary to Director of Child Health Specialty Clinics

Selected Appointments and Professional Memberships:

Association of Maternal and Child Health Programs
 Iowa Public Health Association
 Part C Focused Monitoring and Continuous Improvement – State Advisory Group
 Early Hearing Detection and Intervention - State Advisory Group
 Iowa Positive Behavior Alliance - State Advisory Group

Major Professional Interest(s):

Title V programs for children with special health care needs
 Early intervention services for children birth to three (Part C)
 Children's behavioral/mental health delivery system
 Telehealth for improved health care delivery to rural areas
 Inclusive child care for children with special health care needs
 Program planning, implementation, monitoring and evaluation; and policy development
 Instructional technology and organizational development in public health programs

BIOGRAPHICAL SKETCH

NAME: Holte, Lenore Ann

Education:

Institution and Location	Degree	Year(s)	Field of Study
University of Minnesota, Minneapolis, MN	BS (summa cum laude)	1977	Communication Disorders
University of Minnesota, Minneapolis, MN	MA	1979	Audiology
Syracuse University, Syracuse, NY	PhD	1989	Audiology and Neuroscience

Professional Experience:

- 2001- Clinical Associate Professor, Departments of Speech Pathology and Audiology and Pediatrics, Supervisor, Speech Pathology and Audiology, Center for Disabilities and Development (formerly University Hospital School), University of Iowa, Iowa City, IA
- 1998- Audiology Training Director for ILEND, Center for Disabilities and Development, University of Iowa, Iowa City, IA
- 1998- Audiologist, University Hospital School, University of Iowa, Iowa City, IA
- 1996-98 Audiologist and Research Health Science Specialist, Department of Veterans Affairs Medical Center, Iowa City, IA
- 1991-96 Audiologist, Department of Veterans Affairs Medical Center, Syracuse, NY
- 1992-96 Adjunct Asst. Professor, Syracuse University, Syracuse, NY
- 1989-92 Assistant Professor, Syracuse University, Syracuse, NY
- 1987-89 Instructor, Syracuse University, Syracuse, NY
- 1984-86 Graduate Fellow, Syracuse University, Syracuse, NY
- 1983-84 & 1986-87 Graduate Assistant, Syracuse University, Syracuse, NY
- 1982-83 Audiologist, Glenrose Provincial General Hospital, Edmonton, Alberta, Canada
- 1979-82 Audiologist, St. Paul Public School District, St. Paul, MN
- 1978-79 Audiology trainee, Veterans Administration Audiology Outpatient Clinic, St. Paul, MN

Certification and Licensure:

- 1978 Certificate of Clinical Competence, American Speech Language Hearing Association
- 1996 Audiology License, state of Iowa: #420
- 2003 Hearing Aid Dealer License, state of Iowa #855

Grants and Awards:

- 2000 Bureau of Maternal and Child Health Grant, "Integrated Services for Children with Special Health Care Needs: Universal Newborn Hearing Screening in Iowa." (\$406,000 April 1, 2000 through March 31, 2004)
- 2000 Iowa Department of Public Health Contract, "Training and technical assistance for universal newborn hearing screening." (\$64,000 per year, awarded October 1, 2000 – October 1, 2003)
- 1996 VA Rehabilitation Research and Development Grant, "Changes in auditory abilities with hearing aid use" (3 years, \$262,200)
- 1991 American Federation of Aging Research Grant, "Effects of aging on multifrequency tympanometry" (\$18,000)

Publications (not a complete listing):

- Margolis, R.H., Bass-Ringdahl, S., Hanks, W.D., Holte, L., and Zapala, D.A. (2003). Tympanometry in newborn infants – 1kHz Norms. Journal of the American Academy of Audiology, 14,7, 383-392.
- Holte, L.A. (2003). Early childhood hearing loss: A frequently overlooked cause of speech and language delay, Pediatric Annals, June 2003.
- Holte, L.A. and Margolis, R.H. (2002). Contemporary research in tympanometry, Current Opinion in Otolaryngology and Head and Neck Surgery, 10, 387-391.
- Downey, D., Mraz, R., Knott, J., Knutson, C., Holte, L., and Van Dyke, D. (2002). Diagnosis and evaluation of children who are not talking. Infants and Young Children, October, 2002.
- Bentler, R, Holte, LA, Turner, CW. (1999). An update on the acclimatization issue, Hearing Journal, 52, 44-46.
- Holte LA. (1996). Aging effects in multi-frequency tympanometry. Ear and Hearing, 17, 12-18.

Presentations (not a complete listing):

- Holte, L.A. and Bass-Ringdahl, S. Leadership Training and Mentoring for Graduate Trainees Studying Developmental Disabilities. 2002 Association of University Centers on Disabilities Conference: "Working with our partners: Advancing policy and practice" (Bethesda, Maryland), October, 2002.
- Bass-Ringdahl, S., Moore, J.A., Holte, L.A., and Bentler, R.A., Audibility and the development of infant babble. Presentation to the American Academy of Audiology, Philadelphia, PA, April, 2002.
- Margolis, R.H., Zapala, D.A., Hanks, W.D., and Holte, L.A., Tympanometry in newborn infants; 1kHz norms. Presentation to the American Academy of Audiology, Philadelphia, PA, April, 2002.
- Holte, L.A. , Enrolling children into appropriate early intervention programs by 6 months of age. Presented to the First National HRSA/CDC National Early Hearing Detection and Intervention (EHDI) Conference, Vienna, Virginia, February 2002
- Holte, LA. Populating Iowa's Early Hearing Detection and Interention (EHDI) Database. Presented to the Centers for Disease Control and Preention EHDI Conference, Atlanta, GA, November 2000.
- Holte, LA, Bass-Ringdahl, S, Linde-Fendrich, T. An Update on Newborn Hearing Screening in Iowa. Presented to the Annual meeting of the Iowa Speech and Hearing Association, Des Moines, IA. October 2000.
- Holte, LA. Infant Hearing Screening: The Significance of Early Identification and Intervention with Amplification. Presented to the Aural Rehabilitation Conference, Deartment of Otolaryngology, University of Iowa Health Care, Iowa City, Iowa, September 2000.
- Holte, LA. Newborn Hearing Screening and Early Intervention in Iowa. Presented to the Iowa Perinatal Conference, Des Moines, Iowa, April 2000.
- Holte LA, Rogers J, Hogan C. Effects of High-Frequency Gain on Consonant Recognition. Presented to the American Academy of Audiology. Los Angeles, CA. April 1998.
- Holte LA. Acclimation to hearing aid use. Presented to the International Hearing Aid Conference. Iowa City, IA. June 1997.
- Holte LA, Runge CL, Haskell GB, Hogan C. Changes in auditory abilities with haring aid use. Presented to the American Academy of Audiology. Fort Lauderdale, FL. April 1997.
- Prieve BA, Holte LA. Otoacoustic emissions in infants and children. Presented to the American Academy of Audiology. Salt Lake City, UT. April 1996.
- Holte LA. Aural acoustic immittance measurements in infants. Presented to the New York State Speech-Language-Hearing Association. Kiamesha Lake, NY. April 1990.

BIOGRAPHICAL SKETCH

Name: Salmon , Paul N. (Nick)

Education:

Institution and Location	Degree	Year(s)	Field of Study
Central Missouri State University	B.S.	1969	Speech Pathology
Central Missouri State University	M.A.	1975	Speech Pathology and Audiology
University of Northern Iowa		1988	Post graduate training/licensure in Special Education Administration

Professional Experience:

2002-2004 Technical Assistant/Audiologist, Iowa Early Hearing Detection and Intervention (EHDI) Program

1975-2002 Supervisor of Hearing and Health Related Services, Arrowhead Area Education Agency, Fort Dodge, Iowa

1969-1975 Coordinator of Hearing Services, Joint County School System of Hamilton, Webster and Wright Counties, Fort Dodge, Iowa

Certification and Licensure:

Certificate of Clinical Competence in Audiology (CCC-A) from the American Speech-Language and Hearing Association, 1976

Iowa Department of Education current Licensures and Endorsements: Educational Audiology, Speech Pathology, Special Education Supervision and Director of Special Education

Iowa Department of Health current Licensure to practice Audiology

Accomplishments:

Planned and coordinated the local support and wrote an Iowa Fine Arts Council Grant to bring the National Theater of the Deaf to Fort Dodge, Iowa.

Member at Large of the Iowa Speech and Hearing Association Board of Directors responsible for planning and coordination of two state speech and hearing spring conferences at University of Northern Iowa.

BIOGRAPHICAL SKETCH

Name: Andrews, Emily

Education:

Institution and Location	Degree	Year(s)	Field of Study
The University of Nebraska-Lincoln	B.S.	1999	Education with an emphasis in Speech-Language Pathology and Audiology
The University of Iowa	M.A.	2001	Audiology

Professional Experience:

2001-present Iowa's Early Hearing Detection and Intervention Project
 2001-present Center for Disabilities and Development-University of Iowa Hospital and Clinics, Iowa City, Iowa
 Jan-May 2001 Department of Otolaryngology-University of Iowa Hospitals and Clinics, Iowa City, Iowa
 Jan-May 2001 Audiology Consultants, Davenport, Iowa
 Aug. 2000-May 2001 University Hospital School (Center for Disabilities and Development), Iowa City, Iowa
 Aug-Oct. 2000 Grantwood Area Educational Agency, Cedar Rapids, Iowa
 June 2000 St. Luke's Hospital, Cedar Rapids, Iowa
 1999-2000 Wendall Johnson Speech and Hearing Clinic, Iowa City, Iowa

Training Assignments:

2000-2001 Iowa's Leadership Education in Neurodevelopmental and related Disabilities (ILEND) Trainee, University Hospital School
 Jan-May 2000 Research Assistant for Dr. Jan Moore, Department of Speech Pathology and Audiology

Related Experience:

2000-2001 Iowa's Early Hearing Detection and intervention Project
 Jan 28-30 2000 Aural Rehabilitation Intensive Weekend, Wendell Johnson Speech and Hearing Center

Professional Membership:

Member, American Speech-Language and Hearing Association
 Member, Iowa Speech-Language and Hearing Association
 Member, American Auditory Society

BIOGRAPHICAL SKETCH

Name: Geilenfeldt, Cami N.

Education:

Institution and Location	Degree	Year(s)	Field of Study
Grand View College, Des Moines, Iowa	B.S.	1996	Nursing

Professional Experience:

1998-present Emergency Department Staff RN, Blank Children's Hospital, Des Moines, Iowa

March 2004-present Iowa Hands & Voices Executive Director

Sept. 2004-present Parent Consultant, Early Hearing Detection and Intervention Program, University of Iowa

2002-2003 Occupational Health RN, Maytag Corp., Newton, Iowa

1996-1999 Emergency Department Staff RN, Marshalltown Medical and Surgical Center, Marshalltown, Iowa

May-Aug. 1998 Documentation Specialist, (Formerly Colonial Manor), Baxter Health Care Center, Baxter, Iowa

1995-1998 Charge nurse, Medicine/Treatment nurse LPN/RN, Colonial Manor/Baxter Health Care Center, Baxter, Iowa

Jan-June 1997 Pediatric Home Care RN, Ultimate Nursing, Des Moines, Iowa

June-Dec, 1996 Medical/Surgical/Pediatrics Staff RN, Skiff Medical Center, Newton, Iowa

1996-1999
& 1/03-present Volunteer, Baxter Rescue Unit

Certification and Licensure:

PALS & ENPC certified
ACLS certified
TNCC certified
EMT-B certified #B 06-202-02
RN license #095764

Professional Membership:

EMS committee, member 1999-2003 at Blank Children's Hospital
Interdisciplinary Patient Care Council, Member 1998 at MMSC
Volunteer Mass casualty group for the state at IMMC

Biographical Sketch

Name: Wilkerson, Barbara L

Education:

Institution and Location	Degree	Year Completed	Field of Study
University of Delaware, Newark, DE	BSN	1982	Nursing
US Army PNP Program	PNP	1984	Pediatric Nurse Practitioner

Honors/Memberships:

Iowa Public Health Association
 Iowa Association of Nurse Practitioner
 NAPNAP
 Health Volunteer Overseas
 CDCC-State Advisory Council

Major Professional Interests:

Direct clinical services for families
 Title V programs for children with special health care needs
 Early intervention services for children birth to three (Part C)
 Children's behavioral/mental health delivery system
 Telehealth for improved health care delivery to rural areas
 Program planning, implementation, monitoring and evaluation; and policy development
 Instructional technology and organizational development in public health programs

Research and Professional Experience:

2000 – Present Child Health Specialty Clinic
 Regional and Clinical Coordinator, Health Service Coordinator

1999-2000 Lakes Area Empowerment
 Program Director for Best Care for Better Babies

1989-1996 Upper Des Moines Opportunity
 Title V MCH Pediatric Nurse Practitioner

1995 Health Volunteer Overseas-Bhutan

1986-1989 Darnell Army Community Hospital
 Pediatric Nurse Practitioner

1986-1989 Fitzsimmons Army Medical Center
 Pediatric Nurse Practitioner

1982-1983 Ft Carson, Colorado
 Staff Pediatric Nurse

Part C (Early ACCESS) Memorandum of Agreement
May 15, 2002 - Key excerpts

Collaboration of Service Providers within Early ACCESS System - Early ACCESS Executive Committee (Page 1)

The Signatory Agencies (Department of Education, Department of Public Health, Department of Human Services and Child Health Specialty Clinics) agree to participate on the Executive Committee of the Iowa Council for Early ACCESS for the following purposes:

- *Review and assess ongoing Early ACCESS programs and services throughout Iowa.*
- *Review and assess identified barriers to the effective implementation of programs and services within Early ACCESS.*
- *Implement and assess new and ongoing initiatives.*
- *Identify future directions toward the development of an interagency, integrated system of Early ACCESS for all eligible infants and toddlers and their families.*
- *Meet and communicate regularly for the purpose of carrying out the above responsibilities.*
- *Implement this interagency agreement.*

Early ACCESS Roles and Responsibilities section

Public Awareness/Child Find (Page 3) - *The Signatory Agencies agree that there will be a consistent message for Early ACCESS within and across agencies. As such, the Signatory Agencies agree to participate in the implementation of state, regional, and community activities addressing general public awareness about early intervention as well as procedures for accessing the Iowa system of early intervention services (Early ACCESS). Each Signatory Agency will identify internal contacts for their agency to work with the lead agency, Early ACCESS Grantees, or other Signatory Agencies for participation in public awareness and child find activities and appropriate follow-up. To further promote a common message, the Signatory Agencies agree to provide information and training for their employees regarding public awareness/child find activities to be carried out within and across agencies. . .*

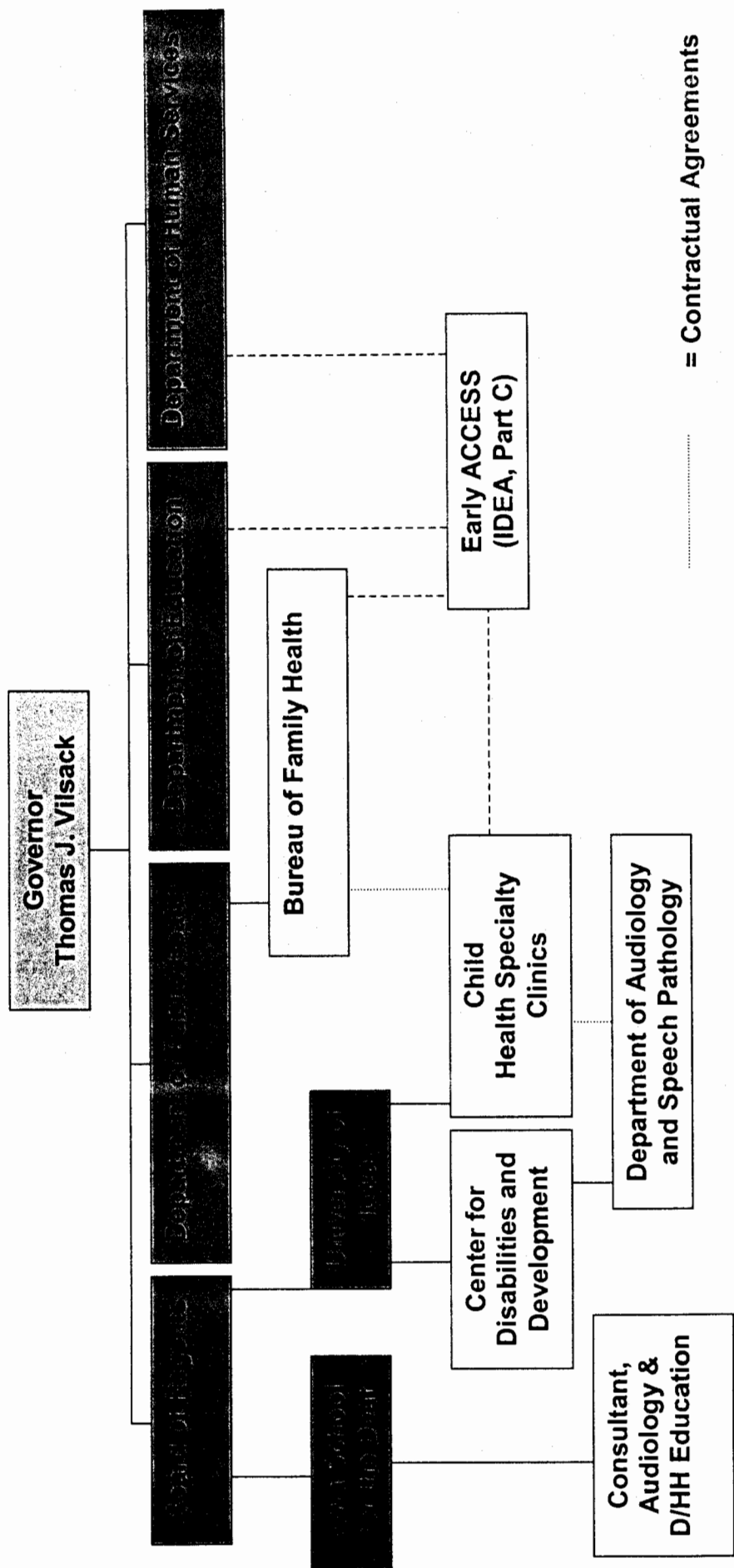
Screening and Identification (Page 3) - *The Signatory Agencies agree to an integrated, interagency screening and identification process that will include agreed-upon clear points of entry and standards and procedures for screening. . .*

Assessment/Eligibility (Page 5) - *Using the definition of the target population of young children to be served included within this Agreement, the Early ACCESS Signatory Agencies shall develop coordinated assessment and eligibility determination procedures that will be utilized across the Departments of Education, Human Services, and Public Health. . .*

Coordinated Services Planning (Page 6) - *Early intervention services are family centered and, as such, families are active participants in all aspects of services. Families are the ultimate decision-makers in the amount, type of assistance and the support they seek to use. . .*

Integrated Service Delivery (Page 7) - *In the implementation of the Integrated Family Services Plan, all Signatory Agencies will implement strategies as appropriated and funded, that assure integrated services for children and their families across all agencies party to this Agreement. . .*

EHDI Organizational Chart



..... = Contractual Agreements

----- = Early ACCESS signatory agency

Iowa EHDI Advisory Committee

The Iowa EHDI Advisory Committee has representation from the following entities:

- Child Health Specialty Clinics
- Iowa Department of Public Health
- Members of the Deaf Community
- Parents of Children who are Deaf or Hard-of-Hearing
- Early ACCESS (IDEA, Part C)
- Deaf Services Commission of Iowa
- Iowa School for the Deaf
- Iowa Department of Education
- Iowa Chapter of the American Academy of Pediatrics
- Iowa Speech and Hearing Association
- Iowa Chapter of the Academy of Family Physicians
- Center for Disabilities and Development
- Iowa Hospital Association
- Iowa Chapter of Hands and Voices
- Iowa Department of Human Services (Medicaid program)
- Area Education Agencies, Teachers of the Deaf and Hard-of-Hearing
- Area Education Agencies, Special Education Directors
- Area Education Agencies, Audiology Supervisors
- Title V
- Private Practice Audiology



Iowa Department of Public Health

Thomas J. Vilsack
Governor

Sally J. Pederson
Lt. Governor

Mary Mincer Hansen, R.N., Ph.D.
Director

October 20, 2004

Jeffrey Lobas, MD
Director
Child Health Specialty Clinics
100 Hawkins Drive, Room 247-D
Iowa City, IA 52242-1011

Dear Dr. Lobas:

On behalf of Iowa's Title V Maternal and Child Health Program, I write in support of Child Health Specialty Clinics' (CHSC) application for the HRSA Universal Newborn Hearing Screening and Intervention grant. This proposal is critical for advancing Iowa's implementation of universal newborn hearing and intervention programs.

Iowa's Title V program is administered by the Bureau of Family Health within the Iowa Department of Public Health (IDPH). The bureau also administers Iowa's Early Hearing Detection and Intervention System with funding from a cooperative agreement with the Centers for Disease Control and Prevention. The CHSC grant project will augment the efforts of the Title V program to assure universal newborn screening and follow-up of infants for whom further assessment is indicated.

The Title V program will collaborate with Child Health Specialty Clinics on this project in several ways:

- Provide data and analysis to the project and assist with the establishment of data sharing procedures between EHDI and Early ACCESS (IDEA, Part C). IDPH serves as the data repository for all newborn hearing screening, rescreening, and diagnostic hearing assessments for children zero to three.
- Provide technical assistance to the project staff regarding the EHDI system.
- Participate in the activities to ensure enrollment of deaf and hard of hearing children in early intervention services. IDPH is one of four signatory agencies for the Early ACCESS interagency collaborative system and the Title V Director serves on the Early ACCESS Executive Committee.
- Communicate with the EPSDT coordinators from the community-based Title V Maternal and Child Health contract agencies regarding EHDI procedures.

The Title V program is committed to be an active partner to improve Iowa's Early Hearing Detection and Intervention System. We look forward to be a part of this worthy and timely project to assure quality developmental outcomes for infants identified with a hearing loss.

Sincerely,

M. Jane Borst, Director
Iowa Title V Maternal and Child Health Program
Chief, Bureau of Family Health

Promoting and protecting the health of Iowans

Lucas State Office Building, 321 E. 12th Street, Des Moines, IA 50319-0075 • 515-281-7689 • www.idph.state.ia.us

DEAF RELAY (Hearing or Speech Impaired) 711 or 1 800-735-2942

Child Health Specialty Clinics

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October 22, 2004

Dr. Jeffrey Lobas
Child Health Specialty Clinics
100 Hawkins Drive, Room 247B
Iowa City, IA 52242-1011

Dear Dr. Lobas:

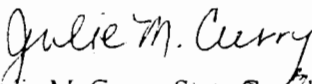
It is my pleasure to offer support on behalf of the Lead Agency of Iowa's IDEA, Part C system (called Early ACCESS in Iowa). It is our intent to support the Early Hearing Detection and Intervention HRSA grant activities that will enhance Iowa's efforts to have effective early hearing detection and interventions. The Early ACCESS system is committed to identifying children with a hearing loss, the needs of the children and their families and providing an array of services to meet those needs and improve outcomes for these children.

The Lead Agency for Early ACCESS (the Iowa Department of Education) has a history of strong collaboration with the applicants for this grant including Iowa's Early Hearing Detection and Intervention program staff. Administrators and Consultants from the Iowa Department of Public Health, Child Health Specialty Clinics, and the Lead Agency meet monthly to address system issues and seek solutions for improving services to young children with special needs. Lead Agency consultants attend EHDI state advisory committee meetings to identify and problem solve issues. The Lead Agency provided data and other supports during last year's efforts to pass state legislation for universal newborn hearing screening.

Once the legislation was passed, we worked together to assure that administrative rules promulgated by the Iowa Department of Public Health were aligned with the language, key stakeholders and intent of a coordinated statewide system of early identification and services. Most recently the Lead Agency and the EHDI program provided guidance to Early ACCESS regional administrators and approved their revised regional procedures to ensure a coordinated system.

In summary, Early ACCESS state consultants will continue to work with staff to implement this HRSA grant to improve the accessibility and quality of services for children with a hearing loss and their families.

Sincerely,


Julie M. Curry, State Coordinator

October 25, 2004

Jeffrey Lobas, MD
Director
Child Health Specialty Clinics
100 Hawkins Drive, Room 247-D
Iowa City, IA 52242-1011

Dear Dr. Lobas:

On behalf of the Bureau of Children, Family and Community Services of the Iowa Department of Education (the Bureau), I write in support of Child Health Specialty Clinics' (CHSC) application for the HRSA Universal Newborn Hearing Screening and Intervention grant. The Bureau administers statewide consultation for audiology, deaf and hard of hearing education in Iowa and Iowa's IDEA Part C system (Early ACCESS). This proposal is critical for advancing Iowa's implementation of universal newborn hearing and intervention programs.

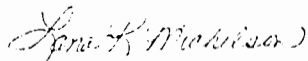
CHSC is one of four signatory parties of Early ACCESS and as such, collaborates with IDE on projects that benefit infants and toddlers with disabilities or developmental delays, including children who are deaf or hard of hearing. The CHSC grant project will augment critical efforts of the Bureau to assure follow-up services for infants identified at birth with deafness or hearing loss.

The Bureau will collaborate with Child Health Specialty Clinics on this project in several ways:

- Provide technical assistance to the project regarding educational services for deaf or hard of hearing children and resources for their families.
- Provide financial resources for contracting with deaf and hard-of-hearing mentors in Project Years 2 and 3.
- Provide graduate level professional development to teachers of the deaf and hard of hearing as well as other Early ACCESS service providers through course offerings such as *Infants, Toddlers and Pre-Schoolers Who Are Deaf or Hard of Hearing: From Identification Through Early Education* by Dr Marilyn Sass-Lehrer.
- Contribute speakers or other supports needed for a statewide Family Conference for Deaf or Hard of Hearing Families in Project Year 2.

The Bureau of Children, Family and Community Services is committed to be an active partner to improve Iowa's Early Hearing Detection and Intervention System. We look forward to actively supporting your project that will assure quality developmental outcomes for infants who are deaf or hard of hearing and provide support for their families.

Sincerely,



Lana Michelson
Chief, Bureau of Children, Family and Community Services

October 22, 2004

Jeffrey Lobas, MD
Project Director, Iowa Early Hearing Detection and Intervention
Director, Iowa Child Health Specialty Clinics (Title V, CSHCN)
Room 247 CDD
100 Hawkins Drive
Iowa City, IA 52242

Dear Dr. Lobas:

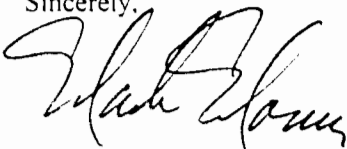
On behalf of the Center for Disabilities and Development, which also serves as Iowa's University Center for Excellence on Disabilities, we are pleased to again partner with Iowa Child Health Specialty Clinics and the Iowa Department of Public Health, Maternal and Child Health (Title V) Bureau to support Iowa's ongoing efforts to evolve an effective and sustainable Early Hearing Detection and Intervention program.

As provided during the past four years of this project, the Center for Disabilities and Development will continue to support the statewide training, technical assistance, and coordination activities of this vital children's public health initiative through the following activities:

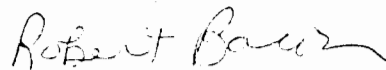
- Provide audiological and systems change training, consultation, and coordination through the efforts of Dr. Lenore Holte and other key staff under her direction
- Provide continuing education opportunities for professionals who serve Iowa's young children who are deaf or hard-of-hearing through partnerships with key faculty
- Provide state-of-the-art, fully accessible conferencing space and statewide telecommunications technologies vital for project training and coordination obligations
- Provide office space for project staff and faculty based at the Center for Disabilities and Development which includes individuals in Child Health Specialty Clinics
- Provide onsite storage space critical for project equipment, educational materials, and supplies
- Provide associated facility services and executive administrative support for these functions and activities.

We look forward to continuing a productive partnership through this important project to improve outcomes for Iowa's children.

Sincerely,



Mark Moser
Administrator
Center for Disabilities and Development



Robert Bacon
Director
Iowa's University Center for
Excellence on Disabilities



October 20, 2004

Jeffrey G. Lobas, MD, Director
Child Health Specialty Clinics
100 Hawkins Drive, Room 254 CDD
Iowa City, IA 52242

Dear Dr. Lobas,

The Early Hearing Detection and Intervention (EHDI) grant proposal is consistent with the overall practice improvement orientation of the Iowa Medical Home Initiative (IMHI). The IMHI seeks to support and facilitate improvements within primary care practices that will benefit children who have or are at risk for special health care needs. Under a medical home model of care, primary care providers will be involved with developmental screening and follow-up for their patients. This means both monitoring youngsters at risk for late onset hearing loss and referring infants who fail hearing screening to Part C early intervention.

The IMHI can facilitate system development for hearing loss through promotion of the medical home as an expected standard of care. The standard requires that practices be able to identify their patients with or at risk for special health care needs, including hearing loss. The standard also requires that patients with special health care needs be linked to necessary community-based services in a coordinated and family-centered manner. The standard is currently not met by most primary care practices. To meet it, educational and economic strategies are being investigated and designed.

The IMHI commits to involving staff from your EHDI project in planning content for any learning experiences designed to spread the medical home standard of care throughout the primary care practice community. The IMHI also commits to a training emphasis on the roles and responsibilities of primary care physicians in follow-up for their patients who fail hearing screening or require subsequent hearing screening. Finally, the IMHI commits to distributing and reviewing with primary care providers any management protocols developed and/or endorsed by the Iowa EHDI Advisory Council or its equivalent.

Your project fits well with IMHI practice improvement priorities as evidenced by already existing collaborations with the Early ACCESS Comprehensive System of Personnel Development initiative, the Department of Public Health's Early Childhood Comprehensive Systems grant, and the Department of Human Service's Assuring Better Child Health and Development early mental health initiative. We believe that the EHDI project is another important collaboration for the IMHI in its pursuit of establishing a medical home model of care.

Sincerely,

A handwritten signature in cursive script that reads "Susie Kell".

Susie Kell, RN, Director
Iowa Medical Home Initiative



Lucas State Office Building – Des Moines, Iowa 50319
515/281-3164 tty/voice – 515/242-6119 fax
dhr.dsci@iowa.gov

October 25, 2004

Jeffrey Lobas, MD
Director
Child Health Specialty Clinics
100 Hawkins Drive, Room 247-D
Iowa City, IA 52242-1011

Dear Dr. Lobas:

I am writing on behalf of the Deaf Services Commission of Iowa to express support for Child Health Specialty Clinics' (CHSC) application for the HRSA Universal Newborn Hearing Screening and Intervention grant. The activities of this proposal are an integral part of advancing Iowa's EHDI project.

I have served on the Iowa EHDI Advisory Committee as the Deaf Services Commission of Iowa (DSCI) representative for four years. In that role, I inform the Iowa EHDI project of current activities within DSCI and work to ensure that EHDI project activities are non-biased and culturally appropriate.

The DSCI will collaborate with the EHDI project on this initiative in several ways:

- Continue to provide DSCI representation on the EHDI Advisory Committee
- Work with EHDI staff to draft letters to parents that communicate screening results at an appropriate literacy level
- Provide technical assistance to EHDI staff, as needed, regarding the provision of non-biased early intervention services
- Collaborate with the Department of Public Health and its partners to develop and integrate protocols for children who are deaf and hard of hearing into the Early Learning Standards for children aged 0-3
- Work with EHDI Advisory Committee and other partners to plan a statewide Deaf and Hard of Hearing Summit
- Collaborate with EHDI project to develop and implement a Deaf and Hard of Hearing (DHH) Mentoring program

The Deaf Services Commission of Iowa is committed to continue its partnership with the Iowa EHDI Project and fully supports the goals and objectives contained in this application.

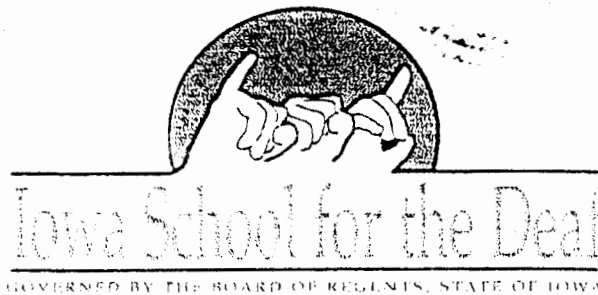
Sincerely,

Kathryn Baumann-Reese
Administrator

Governor Thomas Vilsack
Kathryn Baumann-Reese, Administrator
Deaf Services Commission of Iowa

Lt. Governor Sally Pederson
Dr. Ruth White, Director
Department of Human Rights

"EQUAL COMMUNICATION, EDUCATION AND ACCESS"



Jeanne Glidden Prickett, EdD
SUPERINTENDENT

OFFICE OF THE SUPERINTENDENT

October 25, 2004

Dr. Jeffrey Lobas, Director
Child Health Specialty Clinics
100 Hawkins Drive, Room 247-D
Iowa City, IA 52242-1011

Dear Dr. Lobas:

On behalf of the Iowa School for the Deaf (ISD), let me express support for the Child Health Specialty Clinics (CHSC) application for the HRSA Universal Newborn Hearing Screening and Intervention project. This project is critical to ensure that all newborns receive hearing screenings, and appropriate interventions once hearing loss is identified.

ISD shares the cost of the statewide consultant for audiology and education of students who have hearing impairments, including those who are deaf-blind, with the Iowa Department of Education Bureau of Children, Family and Community Services. The consultant supports our collaborative work with many Iowa agencies to ensure quality statewide services for children who are deaf or hard of hearing. Your proposed project to ensure timely and appropriate identification and follow-up services for infants identified as having hearing loss is an important effort that we want to support through collaboration, with which the consultant can assist.

Iowa School for the Deaf personnel can collaborate with CHSC personnel in several ways:

- Provide technical assistance to the project regarding educational services for deaf, hard of hearing, or deaf-blind children and resources for their families.
- Provide support for establishing deaf and hard-of-hearing mentors in Project Years 2 and 3.
- Assist in the provision of graduate-level professional development to all Early ACCESS service providers through course offerings such as the Fall 2004 course, *Infants, Toddlers and Preschoolers Who Are Deaf or Hard of Hearing: From Identification Through Early Education* by Dr. Marilyn Sass-Lehrer, a nationally-known expert.
- Contribute speakers or other supports needed for a statewide Family Conference for Deaf or Hard of Hearing Families in Project Year 2.

We are committed to working with you to support the Iowa system for Early Hearing Detection and Intervention. We look forward to working closely with you on the project activities. Early identification and strong early intervention programs will strengthen outcomes for all deaf and hard of hearing children and their families.

Sincerely,

A handwritten signature in cursive script, appearing to read "Jeanne Glidden Prickett".

Jeanne Glidden Prickett, EdD

3501 Harry Langdon Blvd. • Council Bluffs, Iowa 51503-7898 • 712-366-0571

Iowa School for the Deaf is an equal opportunity employer

October 25, 2004

Dear Dr. Lobas,

Iowa Hands & Voices works closely with and is in full support of the Early Hearing Detection and Intervention (EHDI) program. Hands & Voices is dedicated to providing unbiased support to families with children who are deaf or hard of hearing. We provide support activities and information concerning deaf and hard of hearing issues to parents and professionals that may include outreach events, educational seminars, advocacy, lobbying efforts, parent to parent networking, and a newsletter. We strive to connect families with resources and information to make informed decisions around the issues of deafness or hearing loss. Family centered services are an essential part of Iowa Hands & Voices.

Universal newborn hearing screening has positively impacted the lives of children and families on many levels. Although parents still grieve, they do not have to wonder how they "missed" their child's hearing loss, nor do they have to deal with the guilt involved with significant speech-language delays. The family and child are not operating from a deficit or delay model regarding language acquisition. With tailored intervention programs and strategies the child can develop language and communication skills at an appropriate developmental pace. The child can benefit from hearing aid use during this critical period for language learning. Language and the ability to communicate impacts many other areas of life – the child's personal-social skills; later academic growth; and sense of self-esteem. The stage has been set for positive growth through early identification and intervention.

We believe it is critical to assure that children who fail a hearing screen are not lost in the system. Iowa Hands & Voices is a place where families can get unbiased information regarding communication options, and explanations of how the "system" works. Follow-up services are a huge part of the success children achieve with their hearing loss. We believe, along with the EHDI program, that it is imperative to not only diagnose early, but to ensure that there are referrals, follow-up, diagnostic evaluation, development of a treatment plan, timely entrance into early intervention services (known as Early ACCESS under IDEA Part C in Iowa), and linking with a medical home for the system to be a success.

Iowa families have benefited greatly from the newborn hearing screening process and also with follow up care they are receiving through the early intervention system. Through the collaborative work of the Early Hearing Detection and Intervention project and Iowa Hands & Voices we can continue to improve the process of early identification of hearing loss and early intervention for our children and families in Iowa.

Sincerely,



Cami Geilenfeldt

Executive Director

Iowa Hands & Voices



**IOWA HEALTH
PHYSICIANS**
IOWA HEALTH SYSTEM

WALNUT CREEK
PEDIATRICS

974 - 73RD STREET, SUITE 30
DES MOINES, IA 50312-1098
515-224-4993
FAX 515-224-1305

October 26, 2004

Jeffrey Lobas, M.D.
Director
Child Health Specialty Clinics
100 Hawkins Drive, Room 247-D
Iowa City, IA 52242-1011

Dear Dr. Lobas:

As the Early Hearing Detection and Intervention (EHDI) Chapter Champion for the Iowa Chapter of the American Academy of Pediatrics, I wish to express my support for Child Health Specialty Clinics' application for the HRSA Universal Newborn Hearing Screening and Intervention grant.

I have worked with the Iowa EHDI system for several years, acting as a liaison to the Iowa Chapter of the American Academy of Pediatrics. I will continue to assist the Iowa EHDI system by:

- Participating on the Iowa EHDI Advisory Committee.
- Educating my colleagues about the importance of newborn hearing screening, follow up, and early intervention.
- Advising the grant staff regarding outreach to pediatricians and other physician groups.
- Assisting with dissemination of best practice protocols developed through the work of this grant.

I believe the work of this grant is important to the health of Iowa's children. I am pleased to be a partner in reaching the goals set forth in your application.

Sincerely,

Amy Lee Wallin, M.D., FAAP
EHDI Chapter Champion
Iowa Chapter of the American Academy of Pediatrics

ALW/amc

**METHODIST
& LUTHERAN**
IOWA HEALTH SYSTEM