Reducing Loss to Follow-up after Failure to Pass
Newborn Hearing Screening
Competitive Supplemental Application HRSA 09-241
Catalog of Federal Domestic Assistance (CFDA) No. 93.251

ILLINOIS
PROGRAM NARRATIVE
2010-2011

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PROGRAM NARRATIVE FOR SUPPLEMENT 2009-2011

INTRODUCTION

Illinois has the 5th largest population and birth rate in the nation. Illinois is 385 miles long and 218 miles wide, and covers approximately 58,000 square miles. There are 102 counties in Illinois, ranging from remote rural areas to major metropolitan cities. Across this large state, approximately 180,000 babies are born each year and are subject to **Public Act 91-0067** Hearing Screening for Newborns Act. The act mandates, "By December 31, 2002, all hospitals performing deliveries shall conduct hearing screening of all newborn infants prior to discharge." Based on national data that suggests at least 2-3 children per 1000, Illinois anticipates that 360-540 infants are born with congenital hearing loss annually. The goal of Illinois' UNHS Program is to identify infants needing diagnosis by 1 month of age, achieve diagnosis by three months of age, and link those infants with hearing loss to treatment and intervention by six months of age. The 2007 data for Illinois, obtained through HI*TRACK suggests the UNHS program is identifying 1.59/1000 live births as having a hearing loss.

Additional program information can be found at: www.illinoissoundbeginnings.org

ACTIVE COLLABORATION / LINKAGES

The Illinois Newborn Hearing Screening Program is a shared legislative mandate therefore collaboration is vital. the following state agencies named in the mandate:

Illinois Department of Public Health Data

UIC- Division of Specialized Care for Children (Title V)

Illinois Department of Human Services/ Illinois Early Intervention (Part C)

Other State Collaborative Efforts

State of Illinois Deaf and Hard of Hearing Commission - agency that works to advance the interests of all citizens with a hearing loss by advocating for systemic improvements, promoting cooperation and coordination among entities serving people who are deaf and hard of hearing.

Hearing and Vision Connections - a statewide training and technical assistance program regarding infants and toddlers who are deaf, hard of hearing.

The Illinois School for the Deaf – State School for the Deaf is to educate students who are deaf or hard of hearing to be responsible, self-supporting citizens.

Other Dynamic Collaborative Efforts

CHOICES for Parents - a statewide coalition of parents and professionals providing immediate access to support, information, and resources to families of children with newly identified hearing loss.

Coalition members include: Alternatives in Education for the Hearing Impaired, Catholic Office of the Deaf, Chicago Hearing Society, Child's Voice, Children's Memorial Hospital, Cochlear Americas, Foundation for Speech & Hearing Rehabilitation, Deaf Access Program Mt. Sinai, Hearing & Vision Connections, HITEC, Illinois Hands & Voices, Illinois Service Resource Center, International Center on Deafness and the Arts, Low Incidence Cooperative Agreement, and Sertoma Speech & Hearing Center.

Illinois Hands and Voices - a parent-driven, non-profit organization dedicated to supporting families that have children who are deaf and hard-of-hearing without a bias toward communication modes or methodologies.

Illinois Deaf Latino Association – a statewide organization to raise awareness and promote appreciation of Latino Culture to the Deaf and Hard of Hearing communities in Illinois through activities, workshops, and cultural event**s**

Illinois Hospital Association / Barbara Haller - represents approximately 200 hospitals and works to advocate for and support hospitals and health systems as they serve their patients and communities.

Birthing hospitals and community providers who participated in the quality improvement learning collaborative: Edwards Hospital, Rockford Memorial Hospital, Adventist Healthcare System, University of Chicago, Bromenn Hospital, Illinois State University, Carle Hospital and Clinic, Southern Illinois University, and St. John's Hospital.

National meetings (EHDI, Investing in Family Support and Hand and Voices National Leadership Meeting) – Illinois Title V agency, DSCC, is housed under the University of Illinois at Chicago. Mission essential travel is permitted by the University.

In the late summer 2009 IDPH began upgrading the state's administrative office and hospitals which are participating in the quality improvement learning collaboratives. The upgrade is to version 4.0 of HI*TRACK allows our state to track outcomes more efficiently. Together DSCC, IDPH, and EI staff track the state progress towards achieving the screening by 1 month of age, diagnosis by 3 months of age and intervention by 6 months of age.

DATA Reflecting Progress

Pursuant to the mandates of Public Act 91-0067 (Hearing Screening for Newborns Act), all 130 birthing hospitals screen newborns by electrophysiological measures and report screening results to IDPH. Illinois is not linked to birth certificates or blood spot reporting. However, through a new cross-check protocol implemented by IDPH where birthing hospitals are required to account for any discrepancies the variance has decreased significantly from 2007-2008. Below if a comprehensive diagram of the screening data progress. (Dated November, 2009)

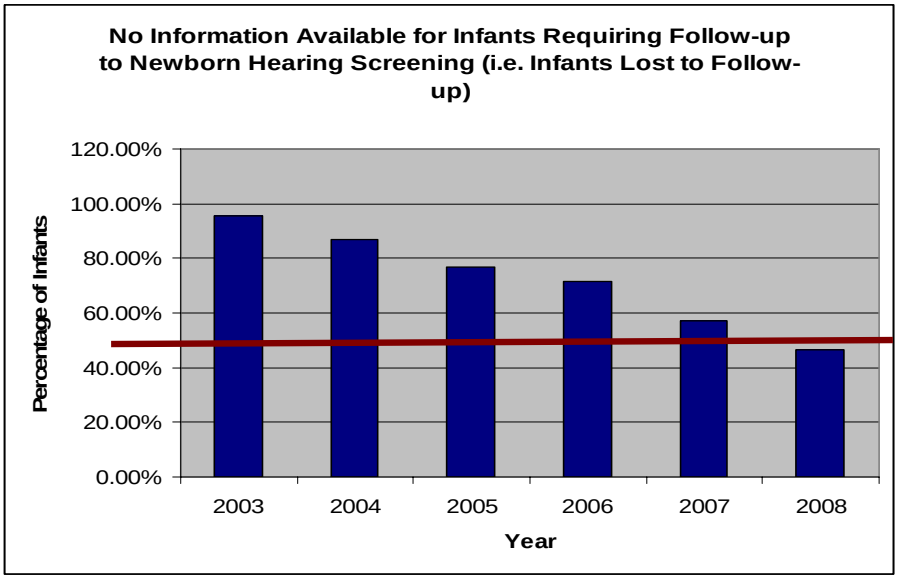
Year	2003	2004	2005	2006	2007	2008	CHANGE
infants reported to IDPH and screened inpatient	160,631	170,205	169,641	171,188	173,703	170,933	
infants reported to IDPH & screened inpt. or outpt.	161,532	170,914	170,385	171,982	174,113	171,443	
% of newborns screened inpt. compared to birth rate	88.07%	94.21%	94.84%	94.84%	96.22%	98.48%	POSITIVE INCREASE
outpatient not screened	1,157	477	321	412	185	187	POSITIVE DECREASE
% of newborns screened by either input. or outpt. compared to birth rate	88.56%	94.60%	95.26%	95.28%	96.45%	98.78%	POSITIVE INCREASE
Referral rates	4.23%	4.29%	3.67%	3.83%	3.48%	4.05%	STABLE

Newborns reported to IDPH	163,224	171,980	171,307	173,077	174,910	172,314	
Live births in IL	182,393	180,665	178,872	180,503	180,530	173,565	
Difference between newborns reported and vital statistics	19,169	8,685	7,565	7,426	5,620	1,251	
Percentage not reported to IDPH	10.51%	4.81%	4.23%	4.11%	3.11%	**0.72%**	POSITIVE DECREASE
Data Status	Final	Final	Final	Final	Final	Provisional	

Infants Not Screened In-patient or Not Re-screened Out-patient

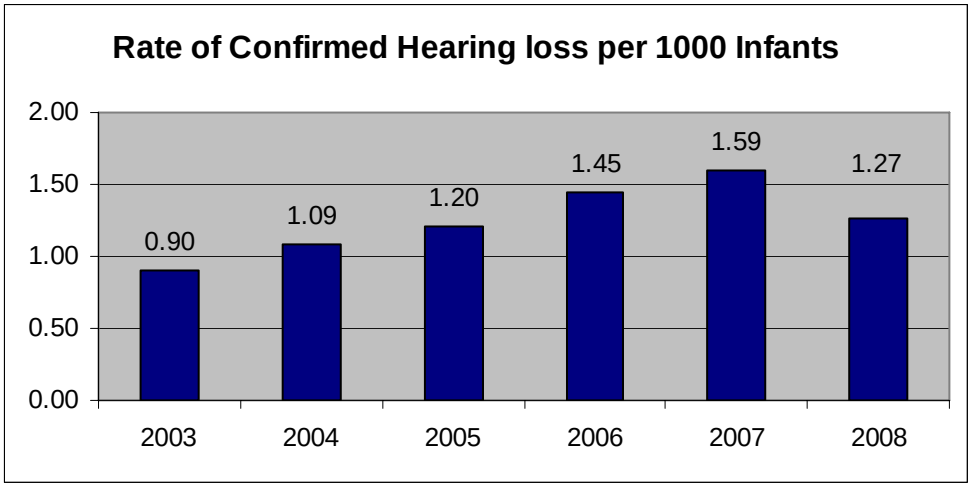
	2003	2004	2005	2006	2007	2008	2009
Broken appointment	0.77%	6.61%	14.36%	16.44%	14.32%	14.53%	12.35%
Refused	1.28%	1.07%	2.60%	2.37%	3.96%	3.04%	0.90%
Scheduled	0.00%	0.00%	0.00%	0.00%	0.00%	0.65%	5.92%
Deceased	0.46%	0.82%	1.08%	1.02%	1.25%	1.37%	0.45%
Follow-up discontinued	2.03%	4.69%	5.09%	8.81%	23.28%	33.62%	2.01%
No information	95.46%	86.81%	76.87%	71.36%	57.19%	46.78%	78.36%

The article by Dr. Tharpe, states, "Almost half (46.3%) of the infants born in 2006 who did not pass their final newborn hearing screen did not complete follow-up and were categorized as lost to follow-up/lost to documentation (LTF/LTD). (citation: *Tharpe, A. M. (2009, March 24). Closing the gap in EHDI follow-up. The ASHA Leader, 14(4), 12–14.)* Illinois broke the barrier for this national statistic for infants born in 2008. While it takes approximately 18-24 months for data to the majority of data to be reported and be reflected in statistical analysis, Illinois shows a trend for decreasing the number of infants lost to follow-up.



The decrease is due to the stakeholder education, quality improvement initiative, the engaging of parents as partners as well as other grant activities. There are areas of follow up which need further investigation and attention so that the screening and the follow up are both "universal".

National incidence statistics suggest that 2-3/1000 children will be identified with a hearing loss by school age. This would suggest Illinois annually has 360-540 infants or children identified. 2007 data suggests only 53-79% of the anticipated number of infants have been identified with a hearing loss and/or reported to IDPH. The following chart suggests an increase in children identified.



2008 and 2009 data is still being reported to IDPH (Data as of November 2009)

Cumulative data for 2003-2009 suggests 37% of the reported hearing losses are unilateral and 63% are bilateral. Data is also broken down by degree of hearing loss. In the graph both unilateral and bilateral hearing loss is averaged together.

Degree of Hearing Loss	Mild	Moderate	Severe	Profound	Unknown	AN/AD
2003-2009 Average	11.43%	45.99%	22.85%	22.29%	3.87%	1.13%

Early Intervention /Part C Data

Despite the low number of EI audiological providers there has been an increase in the number of infants and children who are enrolled with Early Intervention and have a primary or secondary diagnosis of a hearing loss. IDPH refers every child with a confirmed hearing loss to EI. The increase is partially due to the efforts of the Newborn Hearing Program to assist Early Intervention in changing the medical eligibility requirement for hearing loss and enrollment requirements for audiologists.

	March-06	November-06	September-07	November-08
Children 0-3 with an IFSP	94	185	143	259

QUALITY IMPROVEMENT LEADS TO PROGRESS

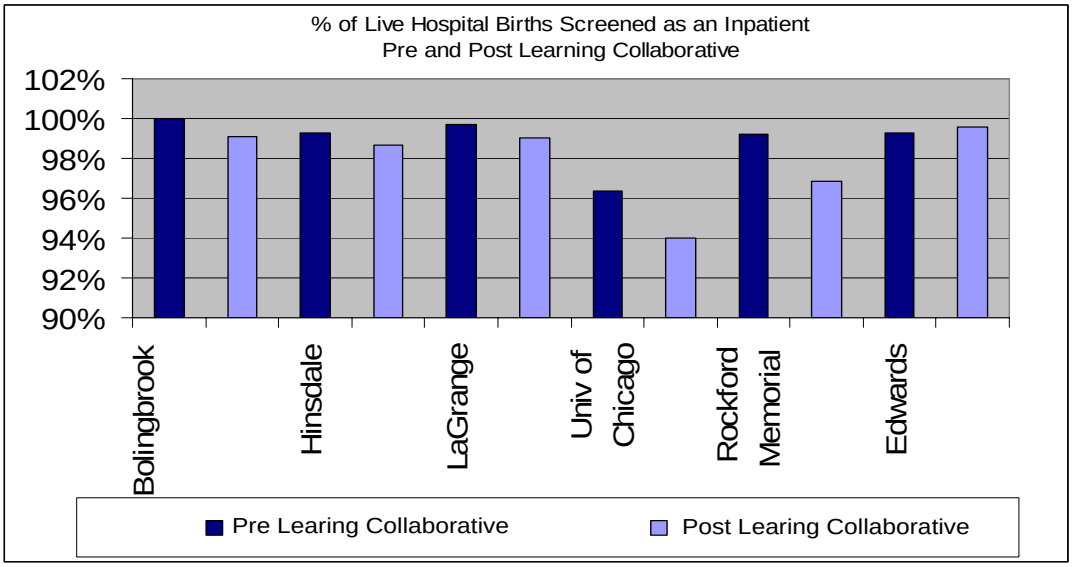
The quality improvement activities since June 2008 have focused on strengthening the links between newborn hearing screening, definitive diagnosis, early interventions, and connection to a Medical Home. Learning and action sessions are completed with analysis of effective changes. The changes lead to improvements and reduction in loss to follow-up. After each cycle, the knowledge is shared with others through professional meetings, annual reports and through the advisory committee to encourage spread. In support of the quality improvement, training, education and public awareness, activities will continue for hospitals, audiologists, physicians, Early Intervention service providers and others, focusing on the need for timely and comprehensive follow-up, reporting and adherence to national and state guidelines.

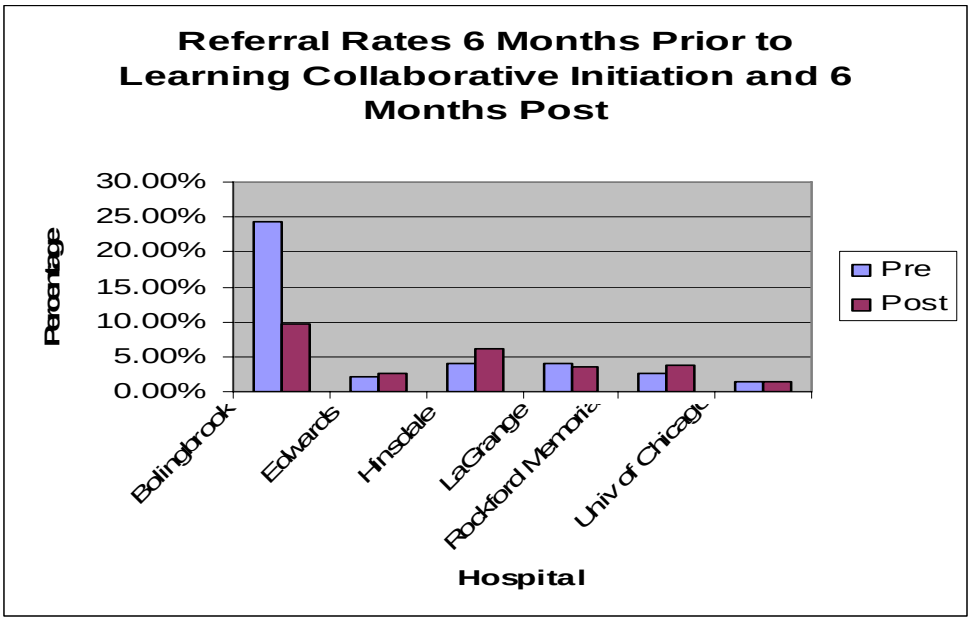
Learning Collaborative Data

Under the grant from 2008 - 2011 Illinois will complete three yearlong quality improvement learning periods. At each learning collaborative meeting, session evaluations are completed by all attendees. Speakers, information presented, and participant interaction are all rated. Feedback from the assessments directs planning and content for future Learning Sessions.

During year one of the grant, participants were from the Chicago/Metro area; year two the central Illinois area; and year three will again be in the Chicago area. Originally year three was to be in the southern part of the state. Through participation in the NICHQ national collaborative the DSCC team realized the obstacles of implementing change strategies around a low incidence disability in lower census birthing hospitals. Central Illinois teams experienced 3-5 week test cycles in order to do a small test of change with families. For a 6 month time period, one central Illinois team, which is a premier center, has only diagnosed one child with a hearing loss.

In year one the DSCC team experienced a learning curve for data collection. Qualitatively, there were numerous accomplishments which will be listed later. Quantitatively, more limited data was obtained. Our team noted the difficulty in obtaining measures that reflect the impact on the 1-3-6 initiatives in a 9-12 month time period. Two examples of quantitative data obtained are:





The quality improvement initiative has given us the opportunity to examine new strategies for unique populations. An example is for lower census birthing hospitals and hospitals without diagnostic evaluation centers within their system the team is working to implement service contracts for outpatient screening and diagnostic services with larger hospitals.

LEARNING COLLABORATIVE QUALITATIVE PROGRESS

Four hospital systems which included 6 birthing hospitals completed the learning collaborative in March 2009.

Three central Illinois birthing hospitals, two University clinics and the Guide By Your Side Program are enrolled in the state learning collaborative for year two.

One hospital system from year one and one from year two are participating with the DSCC team in the national NICHQ project specifically looking at spread for the state.

5 teams have been trained on the importance of parent to parent support and the GBYS program in Illinois.

4 teams provide referral to Guide By Your Side services, at time of confirmation of hearing loss

Each team has been educated on the improvement model, PDSA cycles; developed an action plan and implemented the PDSA model in their setting.

Parent representation and input was achieved in three of the four hospital teams in year one and in all three of the teams in year two.

3 teams implemented a standardized release form to be signed at the diagnostic evaluation which allows information to be release to the Medical Home, EI, IDPH, DSCC and GBYS (i.e. maximizing the opt-in model).

All participating state teams in both cycles utilized scripting the message given the parents when an infant does not pass the initial screening test.

5 of the teams implemented getting a second point of contact for the family.

6 of the teams are working /worked towards making the next appointment for the family and explaining why is it important to keep the appointment before discharge.

3 of the teams have implemented reminder calls before audiological diagnostic appointments that include the reasons why the appointment is important.

4 teams have create expedited appointment slots only for newborns that "did not pass" the newborn screen.

All 25 Part C offices implemented a standardized release form to obtain consent for release of information at first contact with Early Intervention so that information can be shared with IDPH.

Copies of the *The Newborn Hearing Screening Training Curriculum 2 disc set* were given to each of the participating hospitals. Each team shared the discs with the nurse training staff. To date two have implemented portions of the training curriculum.

2 teams sought out and received funding for the purchase of new diagnostic equipment for infants who refer on newborn hearing screening.

Two teams in year one and two teams in year two investigated collaborative efforts to serve children who utilize Medicaid insurance or underinsured children in the community.

Two teams in year two are working towards developing service agreements with rural birthing hospitals. This agreement would provide a link to outpatient hearing screening and diagnostic audiological services.

Clinic specific caregiver informational materials were developed with extensive parent input by 3 teams.

2 teams enlist the support of the visiting nurses (VNA), social workers and/or other community or hospital based systems to follow up infants at risk.

2 teams developed/ revised materials to provide clear communication about next steps in the EHDI process for families of infants who "did not pass". Their models are in development for statewide use as family "road maps."

4 teams are collaborating to develop a hospital nursery "crib card" for parents that conveys screening results and auditory developmental milestones.

1 team has engaged OB/GYN providers regarding the importance of the EHDI process and the need for parents to identify a Medical Home for the infant prior to hospital discharge.

AIM: 1. Reduce loss to follow-up and documentation from the 2006 rate of 71.36% to 46.36% (25% reduction) at the state level. 2. Decrease time to identification to a mean of 3 months, increase the documentation of infants enrolled in Part C or other early intervention to 75% and establish 10 care networks for rural families of infants who do not pass newborn hearing screening in target hospitals and/or communities by March 2011.

Goal: Development and implementation of a community based quality improvement learning collaborative.

Objective	Members Involved	Start Date	End Date	Progress to Date
Enlist the involvement of health care providers, community groups, and stakeholders to participate in a Quality Improvement Collaboration. Participation would be determined through a competitive application process. Participation agreements are signed.	3-4 hospitals and associated stakeholders in metropolitan communities	May 2010	June 2010	In each of the first two years of the grant learning collaborative with 3-4 birthing hospitals and community stakeholders has met to address quality improvement in the respective system from birth through enrollment in intervention services.
Work with the participants in person, via webinars and by conference calls to develop calendar of activities, action plans, data collection and progress summaries	DSCC and enlisted stakeholders	July 2010	March 2011	Monthly meetings with all participants are held via webinar or teleconference; every 3 months meetings with all participants in person; each community group holds monthly meetings.
Identify marketing strategies and resources spread of information gleaned from the collaborative.	DSCC and enlisted stakeholders	July 2010	March 2011	To be completed at the end of the collaborative.

Goal: Education of families regarding decision-making related to the EHDI process utilizing culturally and linguistically appropriate materials.				
Prepare uniform written materials in English and Spanish for families served through the EHDI system (screening, diagnostic and intervention) regarding options for their child who is suspected or has a hearing loss.	Parent workgroup, CHOICES, DSCC, IDPH, HVC	Oct. 2009	March 2011	A parent workgroup was established. Parents reviewed materials from IDPH, collaborative members, DSCC, GBYS and CHOICES then participated in a face to face meeting on November 11, 2009.
Collect, approve, and package an assortment of state and national communication option resources that provide basic information about hearing loss and the array of technology and communication options.	HVC of Part C and DSCC, IDHHC, IDPH	Immediately	October 2009	HVC worked to collect state and national materials that were low/no cost. The materials were reviewed by HVC, EI, &DSCC. A set of materials were agreed upon and packaged for dissemination to all of the local Part C offices through the DSC.
Train designated service coordinators (DSC) in EI regarding available materials and distribution; educate DSCs re: EHDI and GBYS	HVC, IDPH, DSCC, GBYS	Immediately	On-going	Ending August 2009, HVC trained all 25 Part C offices on the role of a DSC specific to hearing (new position); Education re: EHDI &GBYS will occur in Spring 2010
Secure a web-based meeting system and use for training parents and stakeholders.	DSCC	October 2009 secure the system	On-going training	Contract with WebEx. Training for GBYS parent guides and meetings for the learning collaborative have been held using the system. Future use: learning collaborative meetings, training for GBYS, DSC, hospital screening staff

Train newborn hearing screening providers utilizing the Newborn Hearing Screening Training Curriculum (NCHAM/Winston).	IDPH and DSCC	Apr-10	Dec-10	Curriculum has been given to learning collaborative teams. Spread using curriculum and outcome measures begins 2010.
Pay registration fees to the national EHDI conference to be held in Chicago, Illinois, for individuals who are willing to participate in Illinois EHDI enrichment activities.	Parents of children who are Deaf or Hard of Hearing & professionals who work with these children.	Feb-10	Mar-10	Soliciting Parents, DSCs and EI providers with discipline specific expertise. Working with conference planners to enlist parent volunteers who would receive free registration.
Goal: Conduct ongoing evaluation of UNHS to identify problems through data collection and resolve problems with targeted technical assistance.				
IDPH will continue refer all children with confirmed hearing loss to DSCC (Title V), Early Intervention (Part C) and Family Case Management.	DSCC, IDPH, and EI	On-going	On-going	With HI*TRACK 4.0 reports re: EI and DSCC referrals and enrollment is available. IDPH working with EI and DSCC to audit referrals and enrollment.
Improve recording of the PCP at the birthing hospital. (DSCC & IDPH will educate the regarding the importance of having PCP.	DSCC and IDPH	On-going	On-going	All learning collaborative teams have attempted to address this issue; largest barrier is identification of a PCP when the child has Medicaid insurance.
Goal: Provide outreach to audiologists, the state audiology academy and doctoral level audiology students regarding the newborn hearing program, pediatric diagnostics, early intervention and the importance of family participation.				
Encourage audiologists to link with state reimbursement systems by providing enrollment and reimbursement information.	DSCC, IDPH, EI and licensed audiologists	On-going	On-going	EI is schedule to present at the state audiology meeting in January 2010 re: enrollment and services. EI does not have an audiologist on staff, DSCC collaborates to provide technical support in working with audiologists across the state.

Present or assist with arranging presenters for the state academy of audiology meeting or at audiology doctoral programs regarding the newborn hearing program, pediatric diagnostics, early intervention and family participation.	DSCC, IDPH, Illinois Academy of Audiology (ILAA)	April 2010	ILAA Jan. 2011	January 2010 convention to include separate presentations by each of the following GBYS; IDHHC; EI; Carmen Brewer: Syndromes with hearing loss; David Citron – Counseling; and 3 different lectures relating to cochlear implants and children
Goal: Refine the follow-up process so that infants referred from screening receive follow-up diagnostic services by three months of age and intervention services by six months of age.				
Establish a system of referring infants who are not scheduled for follow-up services to DSCC for care coordination.	IDPH, DSCC	April 2010	On-going	MOU between agencies has been examined; Query in HI*TRACK is being written; Protocol for scheduling appointments and reporting to IDPH is being developed.
Goal: Dissemination of educational materials to increase family/PCP understanding of the importance of hearing screening, follow-up diagnosis/intervention/the Illinois system of services.				
Disseminate medical home guidelines/1-3-6 to physicians and parent road maps to families.	DSCC, IDPH, physicians and families of infants who DNP	On-going / Nov. 2009	On-going	NCHAM/ AAP 1-3-6 guidelines modified to reflect IL system have been disseminated to physician. An impact study suggests IL's version complicates the process and does not allow for communication of next steps to parents. Revisions are being addressed by the parent workgroup and state agencies.
Disseminate initial screening and follow-up brochures to families in the birthing hospital.	DSCC	On-going	On-going	Parent workgroup indicates the need for revision of the screening 43.00 and follow-up 43.01 brochures to be more parent friendly.
Develop and maintain a listing of audiologists who provide comprehensive diagnostic services for UNHS infants. DSCC will utilize their approved newborn hearing provider network.	DSCC	On-going	On-going	Analysis of the current enrollment criteria for newborn hearing audiology providers suggests additional information and classifications are needed to assure appropriate referrals. DSCC and advisory committee members will review guidelines and new recommendations will be made.

Goal: Educating parents, professionals and program partners, utilizing tele-education, regarding the Newborn Hearing Program and the aspects from screening through intervention.				
Address providing services to Deaf and Hard of Hearing Community as well as families in the Latino community. (including legal considerations regarding interpreters. Present at the Illinois Deaf Latino Conference on accessing and advocating healthcare in their community.	DSCC, IL Academy of Audiology (ILAA), specialized presenter	Sept-09	Mar-11	Outreach by a Latina GBYS guide has begun; Speakers will be sponsored for the IDLA conference to be held November 21, 2009; Community events for Latino parents of children with a hearing loss are scheduled; Education re: the new interpreter licensure law will be presented at ILAA and via webinar.
Outreach to EI professionals and community organizations where families find support, re: 1) identifying a pediatrician prior to a baby's birth 2) the process for obtaining follow-up to not passing newborn hearing screenings.	DSCC, IDPH, CHOICES, GBYS, HVC	Nov. 2009	Mar-11	Participation with the IDLA, ILAA, HVC parent conferences, and GBYS parent connection meetings is scheduled for November 2009 through March 2010.
Goal: Improve education of new parents of infants who received newborn hearing screening, regarding the importance of hearing screening and follow-up.				
Work with Hands & Voices National to produce, edit and disseminate a motivating video for families to view at the time of failed screen that includes specific information on the Illinois EHDI system.	DSCC, Hands &Voices, CHOICES, & parent workgroup	Sep-09	Mar-11	Oct. 2009 a script for the production was written; December filming will begin; Illinois will have two 30 sec PSAs. – one will include how to access services for diagnostics which is vital due to the absence of a single point of entry in the state for UNHS.
Goal: Development and review of materials that address the cultural and linguistic needs of parents participating in the Newborn Hearing Program available in multiple formats.				
Organize parent workgroup that will review EHDI materials and develop needed materials in both English and Spanish. (Parents will represent children who have chosen various communication modes & live in metropolitan and rural areas of the state.)	Parents of children with a hearing loss, DSCC, IDPH and HVC	Oct-09	Feb-11	October parent participation was elicited; Nov. 5th at the advisory committee meeting a list of documents to be reviewed and created was finalized; Nov. 11th first face to face parent workgroup meeting held. Dec. 8th follow-up webinar scheduled.

Collaborate with state agencies and a parent workgroup to develop and print a resource notebook for families of infants and children who are Deaf or Hard of Hearing.	Parent workgroup, CHOICES, DSCC, HVC and other stakeholders	Immediately	Feb-10	(see above)
Collaborate with state agencies and a parent work group to compile and electronically disseminate a resource listing for professionals who serve families of infants and children who are Deaf or Hard of Hearing.	Parent workgroup, CHOICES, DSCC, HVC and other stakeholders	Apr-10	Dec-10	Following the efforts of the parent workgroup this project will begin in the Spring 2010.
Format all Newborn Hearing Program materials for parents and professionals available on the internet and downloadable to meet ADA guidelines.	Contracted web-design firm, DSCC, parent workgroup	Jan-10	Mar-11	All materials revised or created by the parent workgroup will be publically available in an electronic format at: www.illinoissoundbeginnings.org
Goal: Enhance the capabilities and outreach of a parent to parent support network (Guide By Your Side). GBYS will provide support from a trained, professional parent and connection/enrollment with state and local resources.				
15% in year one and 25% in year two, of all families of newly identified infants and toddlers who are Deaf or Hard of Hearing will receive outreach through GBYS. The guides will provide one-on-one contact between newly-identified families and professional parents by phone, email, instant messaging, video phone or face-to-face.	DSCC, IDPH, GBYS, CHOICES	Immediate/ Start-up	On-going	GBYS training completed in may 2009;10 guides trained; In-take form developed with consent to release information to IDPH; 28 families served from May –Sept. 2009 which is over 10% of infants with confirmed hearing loss and reported to IDPH;

Goal: Improve linkage for families of infants who do not pass the newborn hearing screening and have not received follow-up services within a minimum of 30-days with qualified newborn hearing diagnostic providers enrolled with DSCC.				
Investigate the current MOU and develop a protocol between DSCC and IDPH so infants who are not receiving timely follow-up may be referred to the Title V agency for care coordination (i.e. assistance in schedule diagnostic evaluations).	IDPH and DSCC	Oct-09	Dec-09	An MOU does exist between the two agencies that will cover care coordination; IDPH working with NCHAM to query in HI*TRACK to identify infants not scheduled at 30 days
Assist families in schedule diagnostic evaluations and report care coordination results to IDPH.	IDPH and DSCC	Jan-10	On-going	To begin in January 2010
Goal: Increase the number of licensed audiologists and Au.D students who have appropriate training and mentoring to provide pediatric diagnostic evaluations to infants less than 10 months of age.				
Au.D students and licensed audiologists in the central (more rural) part of the state trained by a leading professional.	ILAA, Au.D training programs, DSCC, IDPH, trainer, and audiologists	Oct-09	Aug-10	Met with Illinois State University and Carle Clinics and Hospitals to develop an outline for training, identify participants and discuss timeline; received ILAA approval for collaboration
Develop mentor relationships between established pediatric diagnostic clinics and licensed audiologists. Provide up to 6 months support; preferences given to outreach areas where healthcare disparities exist.	ILAA, Au.D training programs, DSCC, IDPH, trainer, and licensed audiologists	Jan-10	Feb-11	Will identify participating individuals after advertisement of event at ILAA convention in January 2010

TECHNICAL ASSISSTANCE NEEDS

On a statewide level Illinois continues to struggle to find trained diagnostic and intervention providers with the appropriate training, equipment resources and a willingness to participate with state pay agencies is increasingly taxing. Through newborn hearing, requirements for enrollment with state agencies, supporting continuing education of providers and reimbursement issues have been addressed. However, at this time there is not an adequate solution at the state level to the growing problem of access for all infants and children irreguardless of funding source for services and appropriate pediatric training for professionals.

Measurement of the short term activities that lead to reducing loss to follow-up is a challenge for the program to address. The longitudinal measurements of 1-3-6 are difficult to demonstrate improvement in a 9-12 month timeframe. Quality improvement in the area of newborn hearing is relatively new for the group and measurement of individual PDSA cycles resulting in run measures is difficult. Assistance in addressing valid outcome measures, for short time frames, that are reportable is a needed element.

Funding for current projects correlating to the size of the state and long-term sustainability of the program remains threats to a successful program. Illinois is the fifth largest birthing state in the nation. Spread of quality improvement and other initiatives across such a large state is a challenge for the limited staff and funding under the HRSA grant. Sustainability without a direct state funding source proportionate to the size of the state is an obstacle.

Consistency of data and program reporting across state and federal agencies as well as ancillary program (including NICHQ) would provide the opportunity for comparative analysis, expedited reporting, and reduction in redundancy. Education of EHDI coordinators on the similarities state and federal agencies as well as ancillary programs' reporting and examples of model reporting/applications would assist EHDI coordinators.

CURRENT STAFFING ROLES AND RESPONSIBILITIES

Staffing commitment as it relates to the HRSA grant only is indicated below:

Gerri Clark, MSN, Associate Director for Program Services, **(0.05FTE)** brings over 30 years of professional experience to the Program, including hospital experience, public health, home health and school nursing, as well as 17 years experience working in CSHCN programs in Nebraska and Illinois. Ms. Clark provides leadership for program development, implementation, and evaluation in addition to supervision of care coordination activities in DSCC's 13 regional offices.

Ginger Mullin, Au.D., DSCC - Newborn Hearing Program Coordinator (1.0FTE) has worked in pediatric audiology for 10 years providing diagnostic and amplification services to infants and children as well as providing administrative support. She acts as program liaison among the three agencies involved—IDHS, IDPH and DSCC. As the coordinator, Dr. Mullin promotes the Early Hearing Detection and Intervention Program with primarily diagnostic and

intervention stakeholders and works with parent educational and support organizations in the state. For this grant, she will also coordinate the learning sessions and quality improvement efforts.

Leslie Frederick, Supervisor, Program Support Unit, (0.02 FTE in-kind) is a speech language pathologist. She has worked with the CSHCN Program for over 20 years, as a speech and hearing consultant, and supervises the Program Support Unit, a unit that provides training and technical assistance to care coordination staff throughout the State.

Rita Klemm, MSW, Program Support Unit, (0.10 FTE in-kind) is a Program Support Specialist in the DSCC Administrative Office. Ms. Klemm is involved in promoting Medical Home, facilitating quality improvement, and providing technical assistance as part of the Program Support Unit. Ms. Klemm has over 20 years experience which included work with a private non-profit agency providing services for low-income pregnant women and as a university/hospital based medical social worker.

Additional project staff resources outside of UIC-DSCC include:

IDPH Administration —IDPH Vision and Hearing Programs Administrator, Gail Tanner, Au.D., an experienced audiologist, is the Administrator of the Vision and Hearing Programs for IDPH that includes Newborn Hearing Screening Program, She works daily with physician and audiological follow-up data, tracking issues, funding and staffing needs, and monitoring the overall progress of the Newborn Hearing Screening Program.

Open position: IDPH - Newborn Hearing Coordinator

IDPH – The Newborn Hearing Coordinator is currently a vacant position. This individual is responsible for the administration, tracking, follow-up, data management and reporting activities of the program. On a daily basis, the manager consults with birthing hospitals, manages the electronic data reporting system (HI*TRACK), initiates development of educational programs for screening hospitals and follow-up entities, and assures completed follow-up on referred infants to DSCC and EI for infants with hearing loss.

Partially filled: IDPH Hearing Screening support staff - Staff includes an administrative assistant, office associate, office assistant, two University of Illinois – Springfield graduate interns, and two temporary employees. Additional assistance is provided to the program by the Vision and Hearing Training Manager and two Regional Vision and Hearing Consultants, all of which are audiologists, and contractual trainers through Northwestern Illinois Association. (Both open positions above are due in part to state government hiring restrictions.)

IDHS Administration - Dr. Myrtis Sullivan, Associate Director for Offices of Family Health with IDHS, serves as the co-chair of the Hearing Screening Advisory Committee and member of the Interagency Project Team for the UNHS program. IDHS under the law is responsible for regulatory changes and legislative proposals.

IDHS—Ms. Glendean Sisk, RN, BSN, CRADC, MPH., Interim Chief, Bureau of Maternal-Infant Health, serves as the MCH Program's liaison to the UNHS program coordinator and assists with the development and implementation of training programs for local health department personnel.

Illinois Newborn Hearing Advisory Committee - The advisory committee membership as outlined by the mandate includes: audiologists; Chicago Department of Public Health; Early Intervention providers; Health insurance plans; Illinois Department of Human Services; Illinois Department of Public Aid; IDPH; Parents of children with hearing loss; Pediatric Associations; Persons with hearing loss; Public and private hospitals, and the University of Illinois at Chicago Division of Specialized Care for Children.

During the grant period the committee moved to meetings twice a year and the committee includes active work groups with deliverables.