PROGRAM NARRATIVE 2008

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BACKGROUND AND NEED

Approximately 180,000 babies are born in Illinois each year making its birth rate the 5th largest in the nation. All infants are subject to **Public Act 91-0067** which requires hearing screening of all infants prior to discharge. Based upon national data, it is anticipated that 360-540 infants are born in Illinois each year with congenital hearing loss. The goals of Illinois' Universal Newborn Hearing Screening (UNHS) Program reflect the "1-3-6" plan for Early Hearing Detection and Intervention (EHDI). Illinois data from calendar year 2006, obtained through the HI*TRACK newborn hearing data management software, suggest that the UNHS program is currently identifying 1/1000 live births with permanent, congenital hearing loss. The questions become, where are the other 2-3/1000 infants with hearing loss and why haven't they been found?

The Illinois Newborn Hearing Screening Program is a shared legislative mandate of the Illinois Dept. of Public Health (DPH), Illinois Dept. of Human Services (DHS), and University of Illinois at Chicago – Division of Specialized Care for Children (DSCC). Representatives of these agencies make up the State Level Project Team which provides inter-agency guidance and cooperation for the Program in Illinois. Specifics of each agency are given under the section COLLABORATIVE EFFORTS.

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 DPH every 7 days utilizing HI*TRACK secured email attachment. When comparing screening results reported to the newborn hearing screening program with Vital Records birth rates, 88.3% of the live births in 2003; 94.5% of the live births in 2004, 95% of live births in 2005, and 96.9% of live births in 2006 received the newborn hearing screening. We can see that the discrepancy between the number of live births and the number of babies screened has decreased over the years however, there are still a significant number of infants who are either not screened or who may have been screened but never reported to the Program. This data includes a limited number of home births who, under the mandate, voluntarily received a hearing screening through local hospital access. Table 1, below, is a "snapshot" in time, dated March 11, 2008, of data. Calendar year 2007 vital records data is unavailable at this time.

Table 1

Screening Compliance for Newborn Hearing Screening since effective date of mandate, December 31, 2002

YEAR	2003	2004	2005	2006	2007
Newborns reported to DPH Newborn Hearing Screening	163,217	171,980	171,307	173,048	172,160
Births per Vital Records	182,393	180,665	178,872	177,428	175,857**
Difference	19,175	8,685	7,565	4,380	3918**
Percentage Difference	10.51%	4.81%	4.23%	2.53%	2.28%**
Data Status	Final	Final	Final	Provisional	Preliminary

Data from HI*TRACK as of 3-11-2008

** Preliminary numbers from hospital birthing logs. Vital Records data not yet available.

The data shows great progress in the number of infants reported. The data also suggests that for calendar year 2007, 53 (41%) of birthing hospitals reported less than 98% of births. Six hospitals reported less than 90% of births. Statistically, this could equate to up to 12 infants with hearing loss not screened and/or not reported in 2007.

Per the Illinois law, all infants who refer on the initial hearing screening shall have a second inpatient hearing screening prior to discharge. Those who do not pass the 2nd screening are referred for an outpatient hearing screening and/or diagnostic testing within five days of the Department receiving the hearing screening results. If the infant does not pass the outpatient screening, a full diagnostic assessment including Auditory Brainstem Response testing should be completed prior to 3 months of age. Table 2, below, reflects screening referral rates based on the number of births that were reported to the Newborn Hearing Screening Program for calendar years 2003 through 2006.

Table 2
Screening referral rates calendar years 2003 through 2007

	2003		2004		2005		2006	
Total Infants Reported	163,218		171,980		171,307		173,048	
Infants Screened Inpatient	159,797	98%	169,609	99%	169,077	99%	170,883	99%
Passed	153,025	96%	162,310	96%	162,854	96%	164,354	96%
Referred	6,772	4%	7,299	4%	6,223	4%	6,529	4%
Deceased Prior to Screening	508	<1%	567	<1%	592	<1%	659	<1%
Infants not Screened Inpatient	2,913	2%	1804	1%	1,638	.96%	1,506	.87%
Infants needing out-patient screening	9,685	5.9%	9103	5.3%	7,681	4.5%	8,035	4.6%
Passed	5,101	52.7%	5,499	60.4%	5,388	70.2%	5,422	67.5%
Referred	237	2.5%	236	2.6%	148	1.9%	145	1.8%
Not Screened	4,063	42%	2,780	30.6%	1,667	21.7%	1,624	20.2%
Diagnostic	284	2.9%	588	6.5%	658	8.6%	844	10.5%

Data Source: IDPH Newborn Hearing Program HI*TRACK 3.5 Flow Chart: as of 3-11-2008

Illinois employs a multi-tiered system to reach families when infants refer from the newborn hearing screening which includes initial letters to parents and physicians, 2nd notice letters at 45 days post discharge and the incorporation of Family Case Management agencies for difficult to reach/motivate families. Each year, with the exception of 2006, data shows a decrease in the number of infants requiring outpatient testing and in the number of infants for whom no further information was received past the original inpatient screening results. These numbers underscore the increase in completed follow up and show significant progress for Illinois. Table 3, indicates the follow up status for those requiring outpatient testing 2003 through 2006.

Table 3
Summary of Infants Requiring Outpatient Screening/Follow Up

	2003		**2004**		**2005**		**2006**	
Infants needing outpatient testing	**9,685**		**9103**		**7681**		**8035**	
Infants passing outpatient screening	**3,878**	**57%**	**4,441**	**61%**	**4,279**	**69%**	**4,475**	**69%**
Infants referring from outpatient screening	**195**	**3%**	**221**	**3%**	**128**	**2%**	**124**	**2%**
Diagnostic Testing	**253**	**4%**	**536**	**7%**	**620**	**10%**	**792**	**12%**
Inconclusive	**29**	**<1%**	**18**	**<1%**	**18**	**<1%**	**9**	**<1%**
Unable to locate	**222**	**2.3%**	**191**	**2.1%**	**247**	**3.2%**	**114**	**1.4%**
Refused	**50**	**<1%**	**28**	**<1%**	**44**	**<1%**	**38**	**<1%**
Scheduled	**18**	**<1%**	**112**	**1.2%**	**64**	**<1%**	**26**	**<1%**
Broken appt	**61**	**<1%**	**80**	**<1%**	**94**	**1.2%**	**126**	**1.6%**
Deceased	**46**	**<1%**	**69**	**<1%**	**29**	**<1%**	**28**	**<1%**
Discontinued	**86**	**<1%**	**146**	**1.6%**	**105**	**1.4%**	**172**	**2.4%**
No further information	**3,548**	**36%**	**2,135**	**23.5%**	**1,066**	**13.9%**	**1011**	**12.6**

Data Source: IDPH Newborn Hearing Program HI*TRACK 3.5 dated 3-11-2008

With all the progress Illinois has shown over the years, infants who potentially have hearing loss are still being missed. There are areas of follow up which need further investigation and attention so that the screening and the follow up are both “universal”.

Version 3.5 of HI*TRACK currently being used at the State level does not allow for easy extraction of data regarding follow up timeframes. This has resulted in Illinois’ inability to respond to requests of the CDC regarding numeric data analysis. Version 4.0 of HI*TRACK does allow this data extraction through established reports “designed to provide states the information needed to complete the CDC Survey accurately and efficiently.” Version 4.0 also incorporates a “milestones” summary report which “provides a succinct, comprehensive view of (your) Milestone timeliness.” (NCHAM 2008) Milestones are broken down into categories with counts and percentages.

The DPH Genetic/Metabolic Screening Program has contracted with PerkinElmer/Natus for a commercial Newborn Metabolic Screening (NMS) system to replace an existing out dated custom application. The new system allows hospitals to enter birth data through a Web interface or through an electronic file. The NMS system will provide DPH staff and other stakeholders with more accurate and complete data and quality control; will improve the efficiency of the entire screening testing/follow up process; and will ultimately result in improvements in the lives of newborns and their families as well as time and cost savings for DPH. Automated matching of newborn metabolic screening samples with all births would occur, which would comply with the state mandate of ensuring the screening of every infant. Linkage of the database with other existing data systems including the birth defects registry and newborn hearing screening is planned.

Data collected through HI*TRACK, calendar years 2003-2006, indicate a significant number of infants who passed the newborn hearing screening but who were later identified with hearing loss. Table 4, shows the number and rate of confirmed hearing loss by year of birth based on data extracted from HI*TRACK. Data includes children born out-of-state but living in Illinois, those with congenital hearing loss and those who have been reported with late onset hearing loss after passing newborn hearing screening.

Table 4
Rate of confirmed hearing loss among reported Illinois births

	2003	2004	2005	2006
Number of infants with completed inpatient or outpatient screening	161,062	170,682	170,206	171,851
Number of infants with confirmed hearing loss	128	174	175	195
Rate of confirmed hearing loss/1000 completed screens on Illinois births	.75/1000	1/1000	.99/1000	1.1/1000
Number of Illinois infants/toddlers with confirmed hearing loss born out of state	8	8	6	6
Number of children with identified late-onset hearing loss	13	20	18	11
Number of progressive/late onset losses with risk factors listed in HI*TRACK	2	4	8	4

Data source: IDPH Newborn Hearing Program HI*TRACK 3.5 dated 3-11-08

The data clearly shows a considerable incidence in children identified with progressive/late-onset hearing loss. These numbers reflect that the true incidence of congenital hearing loss identified through Newborn Hearing Screening is considerably less than the rate/1000 births listed in the table 4 as all the children identified with late-onset hearing loss had passed their newborn hearing screening. The data would indicate that the identification of late-onset hearing loss needs to be addressed in Illinois.

When infants/toddlers are identified with hearing loss and made known to DPH, referrals are made to the local Family Case Management (FCM) agency, EI, and DSCC. Sharing data has been a challenge between agencies. Illinois law requires that DPH make the referrals, however HIPAA and FERPA prevent child specific information from being released back to DPH without a signed consent. Upon contact with the family of a child with a confirmed hearing loss, the EI case manager obtains a signed release of information to be sent to DPH with the child's diagnostic information. DSCC provides aggregate numbers back to DPH on the infants/children referred from the program. Illinois is not currently able to match long term intervention goals and process against the identified hearing loss registry. Table 5 shows the status of DPH referrals to EI and DSCC as reported back to DPH. The numbers are not indicative of all infants/children who actually received or are receiving services. Data would show that there has been improvement since the beginning of the program but that much progress still needs to be made in assuring that children with hearing loss are enrolled for intervention services and the data "loop" back to DPH is made.

Table 5
Status of Referrals to DSCC and EI by Year of Referral

Year of Referral	**2003**	**2004**	**2005**	**2006**	**2007**
EI					
referred	**87**	**114**	**187**	**188**	**189**
enrolled	**4**	**19**	**60**	**66**	**60**
ineligible			**2**		**2**
paperwork not returned/no further info	**83**	**90**	**121**	**116**	**127**
declining services		**2**	**3**	**3**	

DSCC					
referred	**87**	**116**	**198**	**192**	**201**
registered	**2**	**3**	**3**		
ineligible		**1**	**1**		
paperwork not returned no further info	**84**	**109**	**167**	**188**	**200**
declining services	**1**		**1**	**1**	**1**
discontinued			**25**		
Moved Out of State/Deceased		**3**	**1**	**3**	

Besides data derived from the state tracking system, in June 2007, a parent survey was piloted with the families of preschoolers with permanent hearing loss who attended a program which provided evaluations for their child and classes for parents. The goal of the survey was to assess the newborn hearing program as perceived by parents of children who are deaf or hard of hearing. Twenty-four families (100%) participated in the session. Parent Comments taken from the survey:

> "Newborn screening was a huge disappointment for us because we were never told that it was not 100% reliable. We thought that if he passed that test then he was fine. Because of this, our son went 20 months of his life with no access to communication."
>
> "Even as I expressed concerns for hearing about 6 – 9 months, the doctor said 'Well, she had a newborn screening and I was never notified she failed, so she is fine.' But he never checked because there was never one given."

These two simple responses to the parent survey indicate the need for pursuing screening for those children who miss the screening prior to discharge and for monitoring of children with risk factors for hearing loss. They also stress the importance of letting parents know that the hearing screening is a “snapshot in time” and for making parents aware of the speech and language developmental milestones.

Illinois data for the children reported to DPH reflects a solid screening program and continual improvement. There are, however, areas which need to be addressed such as:

- Investigating the difference between the numbers of infants reported to the Newborn Hearing Screening Program and those reported to Vital Records;
- Assuring that parents and physicians are aware of developmental milestones regarding language and speech acquisition;
- Assuring parents understand that newborn hearing screening is a “snapshot” in time and not necessarily an indication of future ability to hear;
- Assuring accurate training, notification, screening, and reporting protocols;
- Assuring risk factors are reported;
- Improving the identification of infants with late-onset hearing loss;
- Addressing why there are a large number of infants for which no further information is available/infant has been discontinued due to being “lost”;
- Assuring communication between and amongst at DPH, DSCC, and EI;
- Reporting aggregate numbers annually back to hospitals of their specific data and the status of the program statewide;
- Ability to report specific aggregate data at the request of the CDC.

The proposed project will focus on achieving appropriate and comprehensive diagnosis of infants by three months of age, intervention by six months of age, collecting complete birth, screening and diagnostic data, establishing a mechanism for identification of infants at risk of developing late-onset hearing loss and for identifying those infants who do, indeed, present with late-onset hearing loss and assuring intervention services are provided. In addition, the project will address the status of the new genetic/metabolic screening database and how HI*TRACK can interact with that system and also access other state agency databases to assure that infants with hearing loss receive services. The three agencies involved in the administration of the Newborn Hearing Screening Program, will continue to collaborate addressing key goals to improve the system and to assure timely completion of grant objectives. Data analysis will identify hospital issues which will be addressed by technical assistance through telephone calls and site visits. A summary of reported screening and referral data as well as program and grant activities will be shared with the advisory committee annually.

WORK PLAN

The goals of the Illinois project are as delineated below:

Goal #1 – Assure all live births are reported to DPH Newborn Hearing Screening Program and are represented in HI*TRACK

Goal #2 – Enhance Illinois' ability to generate aggregate data for CDC-EHDI Hearing Screening and Follow-Up Survey (HSFS)

Goal #3 – Enhance the capacity for the Newborn Hearing Screening Program at DPH to communicate with DSCC and EI in tracking and surveillance programs that identify children with special health care needs.

Goal #4 – Assure completed outpatient screenings and diagnostic tests reported

Goal #5 – Assure that progressive/late onset hearing losses are identified

Goal #6: Assure that infants/toddlers with hearing loss are enrolled in an early intervention program

The proposed WORK PLAN, complete with Objectives, Activities, Data/Evaluation, Timeframe, and Responsible Team Members is included as Appendix B.

EVALUATION PLAN

The primary goal of the Project will be to enhance the tracking systems thereby closing the loop between identification, enrollment in intervention services, and notification of the Newborn Hearing Screening Program. Closing the data loop will assure timely intervention for identified infants and toddlers and will enable the Program to assure intervention and to report back to the CDC. Inter-agency data sharing has historically been an area of difficulty and concern in which "thinking outside the box" to achieve goals and discern progress must take place. Obtaining read only access to the CORNERSTONE database, as defined in Goal #3, will assist in the data sharing/cross check process and, along with other activities, will be reflected in the quarterly data matching activities with DSCC/EI as outlined in Goal #6. Additional objectives of the Work Plan will address issues of continuous quality improvement in timely hospital reporting of inpatient screening results, reporting of outpatient screening and diagnostic results, and referrals on infants with confirmed hearing loss.

GANTT project charting software allows for anticipation of needs, timelines, and project activities. It will be used to break down the six GOALS in the work plan into manageable monthly activities which assure clear definition of activity start and completion targets. Objective and activity assignments can be broken down further into areas of individual responsibilities with well defined timelines. An overall timeline for the project goals is attached as appendix B.

In the Project, for each activity, completion dates are clearly defined with many of the activities requiring accountability to the State Level Project Team for timeliness, completeness, and impact on a quarterly basis. Clearly defined progress measures have been established to assure measurable change in the goals and objectives having direct relevance to the reporting of screening and diagnostic data (e.g. goals 3, 4, 5 and 6) with specific corrective measures. Centralized HI*TRACK will provide the historical perspective and data upon which progress will be based. Further, targeted "watch list" hospitals will receive site visit assessment of their individual strengths and weaknesses. The site visits will address specific training needs yielding measurable change based on historical activity for the individual hospital.

For goal #1, the hospitals experiencing the greatest difficulty in timely and complete reporting will receive the greatest intervention. In the first year of the grant, hospitals reporting <95% of all birth with receive quarterly intervention as define in the activities section for Objective 2. In subsequent years, hospitals reporting less than 98% of all births for the previous calendar year will be monitored quarterly with site visits and intervention/retraining activities, as necessary.

Performance regarding goals 2 and 3 will be reflected in the Program's success at reaching hospitals for training and installation of HI*TRACK 4.0 in a timely and effective manner. Accomplishment of these goals and accountability to the grant will be reflected in the Program's ability to respond to the CDC-EHDI Hearing Screening and Follow UP Survey (HSFS) in a timely and complete manner.

The overall goals, objectives, and the evaluation process reflect activities which are specific, measurable, attainable, realistic and time phased (SMART).

PROGRAM CAPACITY

Program capacity is reflected in the strength and collaborative efforts of the State Level Project Team as defined in COLLABORATIVE EFFORTS below. In addition to the longevity of DHS and DSCC in administering their specific programs, DPH, Vision and Hearing Section, has administered the Illinois Child Vision and Hearing Test Act since 1969. There is a long history of implementing and administering statewide screening programs and of collaborative efforts between agencies. The team has been working together for six years to develop and implement Illinois' Newborn Hearing Screening Program and will continue to meet on a quarterly basis throughout the project period to ensure that the proposed work plan is followed and conducted on schedule.

Tracking and follow up activities along with data, HI*TRACK installation and maintenance, helpdesk, training, and referral to intervention assurances will be housed with the DPH central office at 500 East Monroe in Springfield, Illinois. Program infrastructure includes data management and access support through Health Care and Family Services (HCFS), DHS, and DSCC data systems along with centralized HI*TRACK into which all hospitals report. In addition, the efforts of the overall Newborn Hearing Screening Program will be supported through local Family Case Management offices under DHS EI contracted offices statewide as entry points for children in need of services, and the local intake and case management offices of DSCC.

COLLABORATIVE EFFORTS

By the mandates of the Illinois Hearing Screening for Newborns Act, three agencies collaborate on the implementation and administration of the newborn hearing screening and follow-up program. Along with the State appointed Advisory Committee, these agencies steer the efforts of the Program.

The Illinois Department of Human Services (DHS) is the recipient of the Maternal and Child Health Services Block Grant under Title V of the Social Security Act and includes the **Bureau of Early Intervention** (EI, Part C of the Individuals with Disabilities Education Act) and the Office of Family Health responsible for **Maternal and Child Health (MCH)** programs. DHS is identified in the Act as the lead agency for Newborn Hearing Screening and is charged with the responsibility of forming and convening the

Advisory Committee. The Office of Family Health is also responsible for grants to local health departments for the provision of **Family Case Management (FCM)**. FCM staff (often public health nurses) assist with follow-up, referral for diagnostic testing and referral to DSCC and EI services. FCM is supported by **CORNERSTONE** which is a centralized database and data management system housed within DHS and accessible by local FCM. CORNERSTONE includes demographic and EI enrollment information for all children receiving services. In Illinois, families access the EI system through one of the 24 **Child and Family Connection** (CFC) agencies that serve their local areas. This system of CFCs, operating since the fall of 1997, provide intake, service coordination, assistance with eligibility determination and development of the plan of EI services needed by the child and family.

The **Illinois Department of Public Health** has operated a centralized, **Universal Newborn Metabolic Screening Program** since 1980, handling all 180,000 infants who are born in Illinois each year. In 1976, DPH developed the **Regionalized Perinatal Health Care Program**. Through this program, the state is divided into 10 regional perinatal networks that encompass more than 130 birthing and children's hospitals. All delivering hospitals must have a letter of agreement with one of the perinatal network centers. It is the responsibility of each administrative perinatal center to establish and maintain a structure that ensures continuous quality improvement in perinatal care. This structure provides or coordinates an integrated program.

The **Illinois Department of Public Health** has also administered the Illinois Child Vision and Hearing Test Act since 1969 assuring that preschool and school age children throughout the state receive vision and hearing screening. With the passage of the **Illinois Hearing Screening for Newborns Act**, DPH responsibilities were assigned to the Office of Health Promotion, Division of Health Assessment and Screening, **Vision and Hearing Screening Section** because of its history with newborn screening programs, children's hearing screening programs, and its staff of audiologists. DPH is charged with the ongoing training to birthing hospitals, collection of screening data via HI*TRACK, referral and follow-up, data management, and assuring that infants/toddlers diagnosed with hearing loss are referred appropriately for intervention services. Currently, DPH does not directly link newborn hearing screening to birth certificates or blood spot testing. DPH recognizes this need and is working towards this integrated system goal.

The University of Illinois at Chicago – Division of Specialized Care for Children has administered the Illinois Title V **CSHCN Program** since 1937 and currently administers the **Newborn Hearing Screening and Intervention Grant through HRSA**. DSCC works closely with DPH to assure infants have access to diagnostic testing following a screening referral and with Early Intervention to enroll identified children in both the Part C and Title V programs. DSCC continues to collaborate with the **Illinois Chapter of the American Academy of Pediatrics** on a Medical Home grant to provide information to primary care providers about the Medical Home model.

The Newborn Hearing Advisory Committee began meeting in February of 2000 and continues to meet annually. The committee assists the State in establishing minimum standards for newborn hearing screening protocols; recommends further training or certification requirements for audiologists and other professionals who work with infants; recommends policy changes associated with the UNHS system, assists the state with training for hospitals, audiologists, pediatricians, and speech and language pathologists. The Committee established sub-committees to address the issues of standards, training and education, and reimbursement. The composition of the Advisory Committee exceeds the requirements o the Hearing Screening for Newborns Act and includes, in addition to the State Level Project Team, representation of hospitals, universities, audiologists, pediatricians, the Illinois Chapter of the American Academy of Pediatrics, otolaryngology, educators, parents, and representation of the Illinois Deaf and Hard of Hearing Commission. A list of committee members and their affiliations is included as Appendix C. The collaborating agencies function together on the Newborn Hearing Screening Program by bi-monthly State Level Project Team meetings. Together the State Level Project Team works closely with the Advisory Committee to plan, implement, modify, and evaluation the state progress towards achieving the 1-3-6 model.

The collaborating agencies also co-sponsor the **Institute for Parents of Children who are Deaf or Hard of Hearing** along with the **Illinois School for the Deaf, the Illinois Department of Rehabilitation Services and the State Board of Education**. This is a week-long educational program for parents of children (ages birth to 5) who have a moderate to profound, permanent, bilateral hearing loss.

Birthing hospitals and follow up screening diagnostic sources are required to report results (see Appendix D, the Hearing Screening for Newborns Act). A Memorandum of Understanding between DPH and DSCC was updated and signed June 2007.

STAFFING AND MANAGEMENT PLAN

The Illinois project will fall under the Deputy Director of the Office of Health Promotion, Thomas Schafer, and the oversight of the Illinois State Level Project Team. Members of the State Level Project Team include:

Gail Tanner, Au.D., Administrator of the DPH Vision and Hearing Section, holds her clinical doctorate in audiology from Central Michigan University and is a licensed audiologist with more than 20 years of experience in the field. She has responsibility for the State mandated preschool/school age Vision and Hearing Screening Programs, the Hearing Instrument Consumer Protection Program, and the Public Health administration of the Newborn Hearing Screening Program in which she has been involved since before the mandate. She is responsible for data collection, HI*TRACK, tracking, follow-up, referral, and data management portions of UNHS. Dr. Tanner also sits on the Interagency Council on Early Intervention and on the legislatively appointed Task for on Educational Options for Deaf and Hard of Hearing Children.

Gerri Clark, MSN, Associate Director for Program Services, DSCC, brings over 30 years of professional experience to the Program including 15 years experience working in

CSHCN programs. Ms. Clark provides program development, implementation, and evaluation in addition to supervision of regional care coordination activities.

Ginger Mullin, Au.D., DSCC - Newborn Hearing Program Coordinator has worked in pediatric audiology for 10 years. She acts as program liaison among the three agencies involved. Dr. Mullin also sits on the legislatively appointed Task for on Educational Options for Deaf and Hard of Hearing Children.

Dr. Myrtis Sullivan, Associate Director for Offices of Family Health, DHS, is a licensed pediatrician and serves as the co-chair of the Hearing Screening Advisory Committee.

Ms. Beverly English, R.N., B.S.N., M.S., Chief, Bureau of Maternal-Infant Health with DHS, serves as the MCH Program's liaison to the UNHS program.

Janet D. Gully, **Chief of the Bureau of Early Intervention, DHS,** has over 19 years of experience working in various capacities in the field of Developmental Disabilities. Ms. Gully served on the Interagency Council on Early Intervention from 1991-1998.

Under the guidance of Mr. Thomas Schafer, the Illinois project will be directed by Dr. Gail Tanner (Resume Appendix E). Additional DPH Newborn Hearing Staff members are listed below.

Interviews are currently being held to fill the **Newborn Hearing Program Manager** position at DPH. It is expected to be filled by June 1, 2008. The Newborn Hearing Program Manager will be responsible for the day-to-day operation of the statewide UNHS program and accountable to Dr. Tanner and the State Level Project Team as well as the goals and objectives of the grant.

Kathleen Jordan, M.A., licensed audiologist with the Newborn Hearing Screening Program at DPH. She has 10 years of experience in audiology which includes screening at the hospital level. Ms. Jordan oversees the day to day tracking of referral and follow up along with making critical decisions regarding follow up issues in non-regular cases. (Resume attached as Appendix F).

Hearing Screening support staff include 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.

SUMMATION

The Illinois Department of Public Health, along with the partner agencies of the Illinois Department of Human Services and the University of Illinois at Chicago – Division of Specialized Care for Children, is proud of the accomplishments of the Newborn Hearing

Screening Program since its implementation December 31, 2003. Working against funding and staffing limitations, the heart of the program has been in the dedication of the staff and their belief in the difference they are making in the lives of children and families. We ask the consideration of the Centers for Disease Control in providing financial support to further the efforts of assuring that all infants receive hearing screening prior to discharge and are reported to the Department, that those with hearing loss are identified and receive intervention services in a timely manner, and that Illinois can effectively report aggregate data to the national database.

List of Appendices

Appendix A – Perinatal Network Charts

Appendix B - Proposed Work Plan

Appendix C – Advisory Committee Members

Appendix D – Illinois Hearing Screening for Newborns Act

Appendix E – Resume – Gail Tanner, AuD

Appendix F – Resume – Kate Jordan, audiologist

Appendix G – Organizational Chart

Appendix H – Resume Tom Schafer, Deputy Director

Appendix I – Job Descriptions

    I.1 Vision and Hearing Section Administrator – Gail Tanner, AuD

    I.2 Newborn Hearing Screening Program Manager – vacant

    I.3 Regional Vision and Hearing Consultant II – Bellwood Office – vacant

    I.4 Regional Vision and Hearing Consultant I – Kate Jordan, audiologist

    I.5 Administrative Assistant – Jasmine Owens

    I.6 Office Associate – vacant

    I.7 Office Assistant – Derek Williamson

Appendix J – Sample Data Flowcharts generated from HI*TRACK 3.5

    J.1 Flow Chart – All Hospitals

    J.2 Quarterly Hospital Summary Report – individual hospital inpatient report

    J.3 Quarterly Hospital Summary Report – individual hospital outpatient report

    J.4 State EHDI Report for CDC

    J.5 Hospital Summary Report – Annual – individual hospital report

J.6 Hospital Summary Report – Annual – All hospitals

Appendix K – Letters of Support

K.1 – Letter from Janet Gully, Bureau Chief, EI

K.2 – Letter from Gerri Clark, RN, Assistant Director DSCC