

## **GEORGIA'S EHDI PROGRAM**

Since 1999, the Georgia Division of Public Health (DPH) has implemented and sustained legislative, programmatic and reporting measures to improve early identification of and intervention for infants diagnosed with hearing loss. The statewide 95% newborn hearing screening goal was established by statute through the passage of O.C.G.A. § 31-1-3.2. This law also established the creation of the State Advisory Committee on Newborn Hearing Screening (SACNHS) and requires hospitals to report quarterly on the number of births, newborns screened, newborns that passed the screening, and newborns that did not pass the screening. In 2001, DPH implemented the Universal Newborn Hearing Screening and Intervention (UNHSI) program statewide along with a hospital based aggregate reporting system and the publication of *Recommended Guidelines for Universal Newborn Hearing Screening and Intervention*. At the state level, the UNHSI program has three operational components: statewide activities and management, field implementation, and data evaluation. Activities within these components include development of protocols for screening, follow-up and intervention; establishment of training guidelines; initial statewide training and technical assistance by contract consultants; creation of an integrated state-wide data system; development of basic public and health provider awareness campaigns; and a web page with information and linkages. The SACNHS provided a key point of accountability for UNHSI activities through its legislative mandate until it was dissolved in 2005 under a sunset provision.

At the recommendation of the SACNHS, hearing screening equipment was made available on loan to hospitals agreeing to participate in the UNHSI program. Hospitals entered into a Memorandum of Understanding with their Health District office agreeing to strive to conduct hearing screening on at least 95% of newborns by July 1, 2002 and refer those infants

who do not pass the screening for further testing. In addition, each of Georgia's 18 Health Districts designated a UNHSI liaison to handle collaborations with partners and providers within the community and follow-up on newborns that did not pass the hearing screening. Typically, UNHSI liaisons contact hospitals to determine the root cause of the low screening rates or high refer rates. If staff turnover is identified as the problem, UNHSI liaisons offer training and education. For low screening rates, liaisons assist hospitals in determining whether new screening equipment is needed. The State UNHSI coordinator also meets with senior level hospital staff to provide an orientation to the UNHSI program, the terms of the Memorandum of Understanding, and the need for ongoing hearing screening and reporting of the results.

Children 1<sup>st</sup> is Georgia's public health identification, referral and tracking process for infants and children under the age of five with various medical and social factors that place them at risk for poor health and developmental outcomes. The UNHSI program uses Children 1<sup>st</sup> as the follow-up system for newborn hearing screening. In each Health District, the UNHSI liaison works closely with or is the Coordinator of the local Children 1<sup>st</sup> program. Therefore, a core function of Children 1<sup>st</sup> is to ensure that all newborns who do not pass the initial hearing screen receive a follow-up hearing screen and diagnostic evaluation and intervention services by six months of age. Children 1<sup>st</sup> staff contact the families of infants who failed the in-patient hospital screening or post-discharge screening and those infants not screened to assist the family in obtaining proper follow-up hearing services. As needed, Children 1<sup>st</sup> staffs make the referrals for these infants and families to receive follow-up hearing screens, diagnostic evaluation, intervention and other family support services.

Beginning in April 2003, all Georgia physicians and other healthcare providers were

required by law (through notifiable disease regulations<sup>1</sup>) to report the initial diagnosis of hearing loss that is determined or suspected to be permanent and/or progressive in nature in children up to age five. Health care providers report failed results of the initial hearing screening and follow-up screen as suspect cases of hearing loss to the UNHSI program. Audiologists report diagnosed cases of hearing loss by faxing or mailing a completed *Surveillance of Hearing Impairment in Infants and Young Children Form* to the Health District UNHSI liaison or to the State UNHSI coordinator. To date, 74 audiologists representing 40 audiology clinics throughout the state have submitted at least one surveillance form to report a diagnosed case of hearing loss. These audiologists provide clinical evaluations to determine if a hearing impairment has been established. Following such a diagnosis, the audiologist reviews options with the family and primary care provider, and, if requested by the family, starts the process to provide hearing amplification for the infant. The audiologist may also choose to work with Children 1<sup>st</sup> to determine eligibility for post-diagnostic intervention services through enrollment in Babies Can't Wait (Part C Individuals with Disabilities Act, IDEA) and Children's Medical Services (Children with Special Healthcare Needs, Title V).

Several specialized agencies serve the needs of infants and children with hearing loss. Georgia PINES (Parents Infant Network for Educational Service), a statewide program of the Georgia Department of Education, provides assistance to children, birth to age five, in obtaining a full range of assessment services through the state schools and private local providers. Georgia PINES also provides family-centered services, including provision of psycho-emotional support, a home hearing aid program, communication and auditory programs, and support services to parents. Georgia operates three schools for the deaf - two residential schools, the Georgia School

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<sup>1</sup> Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2 which mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-3.02 and 290-5-24 of the Rules of Department of Human Resources, which regulate the reporting of notifiable diseases and metabolic disorders

for the Deaf in Cave Springs and the Georgia School for the Deaf-Blind in Macon and one day school, the Atlanta Area School for the Deaf. Services for children with hearing loss are also available through Part B of IDEA programs in public schools throughout the state and a few privately operated Atlanta area schools.

Parent-to Parent and Family Voices, two national groups for parents of children with disabilities, also offer family support and advocacy services in Georgia. In 2006, a team of parent representatives and professionals established a start-up chapter of the national non-profit organization, Hands and Voices. Two chapter meetings were convened in Atlanta with over 50 attendees. In September, Georgia Hands and Voices held a kick-off meeting for the South Eastern Coastal region. The organization built a contact list of over 100 parents and professionals and is in the process of becoming an established chapter. At the UNHSI coordinator's invitation, two parent representatives attended the CDC EHDI Annual Conference in 2007. A state-funded contract supports the maintenance of a central directory that links parents with resources and provides support groups and information services for children with disabilities.

## **DATA SYSTEMS**

In addition to the reporting of suspect and confirmed cases of hearing loss in children, Georgia's notifiable disease regulations mandate the reporting of all birth defects (ICD-9 codes 740-759.9) and fetal alcohol syndrome (ICD9 code 760.7) to DPH. The Georgia Birth Defects Reporting and Information System (GBDRIS) monitors the incidence, prevalence, trends and epidemiology of birth defects. GBDRIS performs surveillance of birth defects outside of the metropolitan Atlanta area and builds upon a data sharing agreement between DPH and the Centers for Disease Control and Prevention's Metropolitan Atlanta Congenital Defects Program (MACDP) that performs birth defects surveillance and case ascertainment in the five-county

metro-Atlanta area. GBDRIS received more than 30,000 reports of birth defects and identified approximately 470 neural tube defects through passive surveillance by 2007.

Effective January 1, 2007, Georgia law (OCGA 31-12-6 & 31-12-7) and Rules and Regulations (Chapter 290-5-24) required that every live born infant have an adequate blood test for 28 disorders. Blood samples from newborns are drawn by hospitals after the first 24 hours of life and sent to the Newborn Screening Unit of the Georgia Public Health Laboratory (GPHL) for testing. The Newborn Screening Program (NBS) receives an HL7 electronic file containing all test results from the GPHL Newborn Screening Data System daily and makes positive results available to contracted genetics and sickle cell labs at Emory University, Medical College of Georgia and Grady Hospital for confirmation of diagnosis. Until January 2008, the HL7 file of newborn screening results was imported into a state-managed Access database and the genetics follow up contractors either faxed confirmatory results back to NBS or transmitted an HL7 file containing confirmatory tests results and diagnostic information that was then uploaded into the Access database. As of January 2, 2008, all newborn screening results are imported daily into SendSS (State Electronic Notifiable Disease Surveillance System). The NBS reports confirmed diagnoses of metabolic and genetic disorders to GBDRIS, in addition to ensuring tracking, therapy and long-term follow-up for affected children through the follow up contractors. Infants identified through GBDRIS with a confirmed birth defect and those reported from NBS are also reported to Children 1<sup>st</sup> to ensure services are provided through the Children with Special Needs (CSN) programs, High Risk Infant Follow-up (HRIFU), Babies Can't Wait (BCW), and Children's Medical Services (CMS).

To facilitate Children 1<sup>st</sup> staff ability to track infants from in-hospital screen to diagnostic evaluation, DPH developed and distributed an Access database, incorporating core data elements

proposed by the CDC EHDI Data Committee. The database enables Health Districts to generate electronic reports assessing tracking activities as well as letters and “triggers” for follow-up, and to produce a state specific report that measures the Health Districts’ ability to meet target linkage timelines for children with hearing loss and other Children 1<sup>st</sup> criteria. Since 2002, nine Health Districts use the Access database on a voluntary basis for tracking and follow-up. A copy is shared with the state office quarterly for epidemiologic and programmatic analysis. The remaining nine Health Districts use a range of methods to capture hearing screening follow-up information. Therefore, statewide rates through 2007 are based in part on aggregate numbers.

In April 2008, the Office of Epidemiology, Evaluation and Health Information together with the Office of Birth Outcomes will begin the statewide deployment of the newborn surveillance and tracking module of SendSS, Georgia’s web-based child health information system. This population-based surveillance system will be used to identify and monitor at risk children throughout Georgia. A critical feature of the system is the ability to create unique child-based records by integrating electronic interfaces from diverse sources, including electronic records from the Vital Events Information System Birth Registry (VEIS), the Newborn Screening Data System and electronic interfaces with hospital hearing screening equipment. SendSS will be made accessible in 2008 to all birth hospitals, Health District offices, audiologists and primary care providers. SendSS will also be expanded to include the GBDRIS surveillance and reporting requirements for birth defects and a module to capture childhood and adult blood lead surveillance and tracking functionality, which will replace the CDC STELLAR data system currently used by the Georgia Lead Poisoning Prevention Program (GLPPP).

SendSS addresses the Children 1<sup>st</sup> program’s information needs by flagging records of children with medical and socio-environmental risk factors, creating prompts for timely referrals

for follow-up services, and triggering prompts for routine monitoring by private providers. In addition, newborn hearing, metabolic and genetic screening tests and results are linked to each electronic birth certificate, providing population-based newborn screening rates and identifying missed opportunities for screening. Records of children who have positive metabolic screens or fail the initial or follow-up hearing screen are flagged for tracking to follow-up screening, confirmatory testing, diagnostic evaluation, and ultimately for treatment and intervention services. Electronic interfaces for routine transmissions of hearing screening results will allow hospitals to upload all hearing screening results. After each hospital uploads its daily or weekly file of newborn hearing screening tests and results, these records are automatically matched and linked to birth certificate and newborn metabolic screening records. Records of infants who did not pass the initial test in either ear are flagged for follow-up and displayed in the “to-do list”.

Each Health District manages its Children 1<sup>st</sup> and UNHSI “to-do list” of children needing follow-up services. In some cases, a hospital or pediatric clinic may also be granted rights to manage their own “to-do list”. These lists prompt Children 1<sup>st</sup> and UNHSI coordinators to notify the primary care provider and the parents of a child who refers on the initial or follow-up hearing screening. When each coordinator logs into SendSS, the ‘to do’ list displays a queue of the children to be referred for a follow-up hearing screen; who need a follow-up hearing screen test result, who failed the follow-up hearing screen and need a referral for a diagnostic evaluation, who were diagnosed with hearing impairment and need a referral to intervention services; and children referred for intervention services who are not yet enrolled. If a child who failed the in-hospital test has not received a follow-up test by one month of age, despite the initial attempts to contact the family and pediatrician, Health District staffs are prompted to resume attempts to contact the family and provider and ultimately to flag the child’s record as ‘lost to follow-up’ if

no response is obtained. SendSS also flags infants with a risk factor for late onset hearing loss and prompts the coordinator to send an automated letter to the parents and the child's primary care provider requesting the child receive a diagnostic evaluation before three years of age. This letter is generated every six months until a diagnostic evaluation is entered into SendSS.

Through this series of prompts for actions (i.e., phone calls, letters, etc.), the primary care giver and primary care provider of the child at issue will be contacted routinely to ensure the child receives timely diagnosis and intervention services. When a child's record is updated with the requested information (e.g., follow-up screening results), that child is removed from the "to-do list" or a new prompt is created requesting completion of the next activity for that child (e.g., referral to a diagnostic evaluation).

Incoming records are processed through a robust probabilistic de-duplication and matching software application, Netrics, to create linkages between existing child records and incoming data from each electronic interface or to create new child records. Also, each record containing an address for a child will be assigned a latitude and longitude for geo-spatial analysis after processing by enterprise level geo-coding software. Piloting the system began in November 2007, with the assistance of the Dalton Health District; PedsCare, a pediatric clinic serving Dalton's population; T.C. Thompson's Audiology Clinic; a CMS clinic; and Hamilton Hospital, the primary birthing hospital serving the Dalton Health District, and Northside Hospital, Georgia's largest birthing hospital with over 18,000 births annually. Starting in April 2008, roll-out to all Health Districts, hospitals, and private providers will take place.

## **NEEDS ASSESSMENT**

As a result of these and other initiatives, the statewide hearing screening rate for all babies prior to discharge increased from about 30% in 1999 to 98% in state fiscal year 2004.

Since 2004, the state wide screening rate has remained stable at slightly above 98% with an average refer rate of about 4%. The State UNHSI coordinator monitors statewide screening rates on a quarterly basis and collaborates with the Health District UNHSI liaisons to provide education and training to hospitals with screening rates below 95% or to hospitals with refer rates above 4%. In SFY07, 36% of hospitals reported an average refer rate above 4%, and 9% of hospitals had average screening rates under 95%.

In 2006, there were 143,779 in-hospital live births reported from 90 birthing hospitals through the aggregate reporting system to the UNHSI program. Of these, 98.5% of infants were screened for hearing loss and 3.8% of those screened did not pass the initial screen. The Vital Records Section estimates 0.4% of all 2006 births occurred out-of-hospital, thus the hearing screening status of approximately 650 infants per year is unascertainable. A procedure to ascertain the hearing screening status of home births is needed to ensure all home births are screened. The ethnic diversity of Georgia's population is reflected in its births: 64% of all births are identified as Caucasian, 32% as African American, 4.1% are of other racial categories and, about 15% of all new births are from mothers of Hispanic origin.

In SFY 2007, Children 1<sup>st</sup> reported 5,646 infants were referred as not passing the hospital hearing screen. Of these, 3,749 were tracked to an outpatient hearing screen and 585 did not pass the outpatient screen. Subsequently, 435 children were tracked to a diagnostic evaluation, of which 158 were identified with hearing loss, and 147 were linked to an intervention program. These data indicate approximately 34% of infants who failed the initial hearing screen were not tracked to a follow-up screen. Of the infants who did not pass the follow-up screen, 26% were not tracked to a diagnostic evaluation. Children diagnosed with hearing loss were not tracked to intervention services only 3.7% of the time.

The Newborn Screening Unit of the GPHL tests blood spot samples from at least 97% of babies. In 2007, approximately 170,000 newborn screening specimens were submitted to GPHL for testing. Approximately 23,000 were abnormal and referred to the NBS follow-up contractors for retrieval and follow-up testing. A total of 255 infants were diagnosed with one of the 28 mandated disorders. The expansion of the screening panel produced an additional 31 diagnosed cases, 24 of which were diagnoses of Cystic Fibrosis. Approximately 200 infants were diagnosed with other variant metabolic or hemoglobin abnormalities, not all requiring treatment.

Despite Georgia's success in meeting its screening objective, the UNHSI Program cannot account for the follow-up hearing screening status of up to 34% of infants who failed their initial hearing screening at birth or to accurately determine the number of children truly lost to follow-up. It is difficult to trace children identified through the Surveillance Form back to the initial hospital screen or follow-up hearing screen, in part because families who move to a new jurisdiction do not typically inform the Children 1<sup>st</sup> coordinator of their change in address. Children 1<sup>st</sup> staffs are often unable to identify missed opportunities for screening and infants who failed the in-hospital hearing screen if individual screening results are not reported. To address this, some Health District Children 1<sup>st</sup> staff request monthly logs of all infants screened from each birthing hospital to validate the results, a consuming activity for hospital staff.

An estimate of the number of infants and families linked to intervention services is difficult to ascertain using existing data collection system. Despite the close tie between Part C services and the Children 1<sup>st</sup> program, data collected on children identified with hearing loss is limited to the screening and diagnostic evaluation services. FERPA (Family Education Rights and Privacy Act) and IDEA Part C regulations limit the ability to obtain medical information on hearing impaired children who are referred for intervention services. A Memorandum of

Understanding and uniform parental consent forms are needed to allow public health to obtain medical information on children diagnosed with bilateral, severe to profound hearing loss receiving Part C services through BCW or CMS. Office of Birth Outcomes staffs will convene a working group to establish a uniform process for documenting parental consent for sharing health information on children enrolled in BCW so that intervention information for children diagnosed with hearing impairment can be added to the child's health profile.

## **PROPOSED WORK PLAN AND METHODOLOGY**

This proposal addresses the need for funds to proceed with the deployment and implementation of the Children 1<sup>st</sup>, Newborn Screening, and UNHSI surveillance and tracking functionality of SendSS, as well as provide support for on-going epidemiological analysis and reporting of newborn hearing screening data, surveillance system evaluation, and programmatic evaluation using SendSS data starting in Year 1 of the Grant cycle.

### **Description of Year 1 activities**

Activities in Year 1 of this grant focus on making SendSS accessible through training and user authentication to all Georgia birthing hospitals, audiologists and pediatricians starting in July 2008, and to all 18 Health District Children 1<sup>st</sup> and UNHSI staff as well as each of the 159 county health offices beginning in April 2008. Training for all SendSS users is mandatory. As described in Appendix C each training session will also cover the Children 1<sup>st</sup> and NSB functions that are relevant for each end-user type, including obtaining access to a child's heel stick screening results, confirmatory tests and diagnosis, follow up actions and to-do lists. Funds from this grant will be used to hire a trainer to perform individualized on-site, web-based or regional class room training sessions tailored to the needs of each type of end-user.

Georgia's ability to establish and improve methods to identify, match, collect and report

standardized unduplicated individual identifiable data hinges on the success of the statewide deployment of SendSS and the ability of DPH to engage birth hospitals, audiologists, pediatric and family practice clinics, as well as all Health District and County Children 1<sup>st</sup> and UNHSI staffs to report individual hearing screening results, follow up test results, diagnostic evaluations and intervention information directly into SendSS. All birth hospitals will be encouraged to submit automated newborn hearing results on a weekly or daily basis. Legislation was proposed in March 2008 requiring hospitals to submit to DPH electronic records of newborn hearing screenings on all infants screened. If this legislation is enacted in the current legislative session, all birth hospitals must have access and be trained to upload hearing screening results directly into SendSS by July 1, 2009. As each birth hospital is approved to upload hearing screen results, these records will also be matched and linked to electronic birth records in SendSS.

Since January 2008, daily imports of newborn screening test results are matched and linked to electronic birth records to create an individual child record in SendSS. The three agencies contracted to provide follow up on positive results of the heel stick test use SendSS to log the follow up activities for each child who tests positive for sickle cell disease or a metabolic condition. Epidemiology staffs consulted with Dr. Craig Mason on the design of an evaluation protocol to assess the sensitivity and specificity of the Netrics matching algorithm currently used to match SendSS records to create one unique record per child. This evaluation will focus on the linkage of electronic birth records with newborn screening records in real-time and will be expanded to assess the quality of the linkage between automated newborn hearing screening records and electronic birth records. Protocols to de-link mismatched records have been defined and will be implemented in SendSS so that false matches can be corrected.

In addition, the State UNHSI Coordinator and Birth Outcomes Epidemiologist will

routinely monitor these linkages to determine 1) the error rate and adjust the internal matching protocols accordingly, 2) missed opportunities for screening, 3) the efficiency of the matching process, 4) the timeliness in submitting results and of the linkage to birth certificate records, and 5) the number of infants born in a Georgia hospital who reside out of state and need follow up services. The results of these analyses will be used to identify hospitals and providers with high loss to follow-up rates for targeted training or education, to initiate and establish data sharing agreements with neighboring states, and to propose improvements in the flow of information into and out of SendSS. Programmatic and surveillance indicators will also be defined and analyzed routinely to assess the program performance benchmarks for Children 1<sup>st</sup>, UNHSI, and the NBS. A monthly report will be disseminated to hospitals and providers and used to improve reporting practices and hospital or provider screening practices.

SendSS will be expanded in 2008 to incorporate GBDRIS surveillance and reporting requirements as well as to provide GLPPP childhood and adult blood lead surveillance and tracking functionality. As a result of the recent restructuring of the Division, placing all health information systems in one Section, plans to create a common interface between SendSS and Georgia's Immunization Registry (GRITS) are also taking shape.

### **Description of Year 2 and 3 Activities**

Year 2 and 3 activities will focus on implementing quality assurance methods to improve reporting practices, evaluating the surveillance system attributes, and performing routine epidemiological analyses of the UNHSI, NBS, GBDRIS and GLPPP data

### **GOALS AND OBJECTIVES**

The overarching goal is to enable children with hearing loss to acquire communication skills within a defined typical range by school entry through early detection and identification by ensuring that: a) all newborns receive a hearing screen prior to hospital discharge, b) all children

who do not pass the hospital hearing screen receive a follow-up hearing screen by one month of age, c) all children who do not pass the follow-up hearing screen receive a diagnostic evaluation by three months of age, d) all children diagnosed with a hearing impairment are enrolled in an intervention program by six months of age and are linked to a medical home. This goal mirrors proposed Healthy People 2010 UNHSI goals and MCHB milestones related to screening, follow-up, clinical assessment and intervention.

**Goal 1: To implement the newborn surveillance and tracking module of SendSS with the goal of minimizing the number of infants lost to follow up by monitoring the status and progress of every infant through the EHDI process or through follow-up by the Newborn Screening Program, Children1st, GBDRIS or GLPPP.**

*Objective 1.1 To deploy the EHDI component of SendSS statewide, including monitoring newborn hearing screening results for all births, audiological diagnosis, medical evaluation, and early intervention services.*

Beginning in April 2008, UNSHI functionality will be rolled out to all District and county health departments, web-enabled birthing hospitals and interested audiologists and pediatricians. Access will be limited to users with role-based access rights. Detailed communication and implementation plans are being developed by Epidemiology Section and Office of Birth Outcomes staffs. Educational materials and a training module will also be developed. Training will be performed through a combination of methods, including a train the trainer approach, web-based training sessions and class room settings. Funds from this grant will be used to hire one support staff to provide help-desk support and training to new users. Monitoring the status and progress of every birth through the three components of the EHDI process will be performed through SendSS by the State UNHSI Coordinator with the assistance of the Birth Outcomes Epidemiologist. Automated ticklers, notifications and prompts incorporated into SendSS will improve the ability of the UNHSI program to identify missed opportunities for hearing screens, children who failed a hearing screening, the need for prompt

follow-up, confirmed diagnoses of hearing loss, and the need for intervention services.

*Objective 1.2 To deploy the Children 1<sup>st</sup> component of SendSS statewide, including the risk factor identification, referrals for CSN and other services, family needs assessment, routine monitoring at established intervals, and tracking through early intervention services.*

Activities for this objective will be performed concomitantly with Objective 1.1.

*Objective 1.3 To deploy the NBS components of SendSS statewide, including integration of confirmatory testing and follow up functionality with the Children 1<sup>st</sup> monitoring and tracking functions.*

Activities for this objective will be performed concomitantly with Objective 1.1.

*Objective 1.4 To develop, test, pilot and implement the GBDRIS component of SendSS, including integrating GBDRIS surveillance with the Children 1<sup>st</sup> monitoring and tracking.*

Activities for this objective will be performed as described in Appendix D.

*Objective 1.5 To develop, test, pilot and implement the GLPPP component of SendSS, including integrating GLPPP surveillance with the Children 1<sup>st</sup> monitoring and tracking functions.*

Activities for this objective will be performed as described in Appendix D.

**Goal 2. Achieve high level of system functionality, acceptability, and data integrity through ongoing analysis and quality assurance activities to measure system performance at hospital, district and state level.**

*Objective 2.1. To evaluate and monitor methods to identify, match, collect, and report standardized unduplicated individual identifiable data on screening results by integrating information across NBS, birth registration, automated hearing screening and SendSS.*

As described in the Year 1 Work Plan, daily imports of newborn screening test results are matched and linked to electronic birth records to create an individual child record in SendSS.

Epidemiology staffs are developing an evaluation protocol to assess the sensitivity and specificity of the Netrics matching algorithm used to create one unique record per child. The UNHSI Coordinator and Birth Outcomes Epidemiologist will routinely monitor these linkages to determine 1) the error rate and adjust the internal matching protocols accordingly, 2) missed opportunities for screening, 3) the efficiency of the matching process, 4) the timeliness in submitting results and of the linkage to birth certificate records, and 5) the number of infants

born in a Georgia hospital who reside out of state and need follow up services. The results of these analyses will be used to identify hospitals and providers with high loss to follow-up rates for targeted training, to establish data sharing agreements with neighboring states, and to propose improvements in the flow of information into and out of SendSS.

*Objective 2.2. In 2008, review quality assurance benchmarks to identify individual reporting sources not meeting data standards, common reporting problems, and identify hospitals with inadequate screening rates for root cause analysis, education or technical assistance.*

SendSS is a tool to improve screening of newborns and to assist public health programs and private providers in case management through tracking and referral functions. It is important that consumers and providers of information are satisfied with the functions SendSS provides and the type and amount of information each user is permitted to access. Each type of user will be surveyed about the ease of use, accessibility, functionality, features, and barriers to reporting through SendSS. Protocols to address concerns about confidentiality with respect to sharing identifiable medical information across data systems are being developed. DPH legal counsel has been consulted for guidance on meeting HIPAA and FERPA requirements. A protocol to routinely analyze SendSS data to measure data quality, timeliness, completeness, and other program performance indices will be developed and implemented for UNHSI, NBS and Children 1<sup>st</sup>. Reporting sources providing incomplete, inaccurate or untimely data will be identified and solutions to improve data quality and reporting practices will be proposed.

**Goal 3. Assess the health outcomes of children identified with hearing loss, birth defects or metabolic disorders through SendSS.**

*Objective 3.1: In 2009 and on-going, assess screening coverage rates of infants needing genetic, metabolic, or hearing screening, diagnosis, and intervention or follow-up services, and assess service provision levels and identify missed opportunities for follow up by service type, geographic area and sub-population.*

To measure the effectiveness of SendSS as a mechanism for reducing loss to follow up and to determine referral rates for follow up services, a representative sample of children

identified during a specified time frame with birth defects, metabolic conditions or hearing loss will be compared to children identified by districts and tracked through their clinical information systems for the same time period. The numbers and percentages of children who were referred to and received specific services and timeliness of identification, reporting and referrals will be calculated, and missed opportunities will be identified by comparing lists of individual children from each sample. The goal is to assure that each child identified by a district is also identified by SendSS, has been referred into Children 1<sup>st</sup> and then on to CSN as appropriate. In addition, a subset of children identified with hearing loss, PKU or neural tube defects through SendSS will be selected and referrals to and provision of follow-up services will be evaluated and monitored by comparing the SendSS data to case data from multiple sources, including UNHSI, GBDRIS, Georgia PINES, BCW, CMS, HRIFU.

The quality of data collected by GBDRIS and the methods used for case ascertainment and data collection will be evaluated by comparing the numbers and types of birth defects ascertained through GBDRIS with those generated by active surveillance through MACDP for the five-county metropolitan Atlanta area. These will be compared with reports in SendSS. MACDP data will be linked to district databases from CSN programs in order to determine whether children identified through MACDP are obtaining appropriate services in the five-county Atlanta area. In addition, quarterly case-finding audits will be conducted at the six regional perinatal care centers to identify potential cases from logbooks and other case-finding sources for comparison with the case list created by GBDRIS.

*Objective 3.2: In 2010, design and conduct an evaluation study comparing hospital discharges and Medicaid claims with services identified through SendSS*

Through an agreement between the Department of Community Health, responsible for insuring nearly 2 million people, and DPH, the Birth Outcomes Epidemiology Unit links

Medicaid claims datasets to vital records data to evaluate the effectiveness of perinatal case management and pregnancy-related services in preventing adverse birth outcomes. All hospitals, ambulatory, surgical, and obstetrical facilities licensed by Georgia, except federal hospitals, are required to submit records of hospital discharges derived from the Uniform Billing Statement (UB 92) to the Georgia Hospital Association. Hospital discharge records of infants and children with ICD-9-CM codes of reportable birth defects and hearing loss will be selected by hospital and date of birth and linked to Medicaid, the birth record and SendSS records to determine health outcomes and the type and frequency of special needs services administered.

### **COLLABORATIVE EFFORTS**

The Birth Outcomes Unit, Epidemiology Section, and the Health Information Systems Section will oversee the training and deployment of SendSS with the assistance of the NBS and the Children 1<sup>st</sup> Programs of the Office of Birth Outcomes. Epidemiology staffs will apply their expertise in data linkage and matching to assess the record matching algorithms. Epidemiologists will analyze the NBS, UNHSI and Children 1<sup>st</sup> data and perform the evaluation of the surveillance system attributes and related program performance indicators. Staffs representing each Section meet on a weekly basis to discuss the status of SendSS, monitor barriers to its progress and identify solutions. Meeting minutes are distributed and a monthly status report is submitted to executive leadership with requests for assistance as needed.

For over six years, the Office of Birth Outcomes has partnered with the Epidemiology Section. Each of the surveillance and tracking modules of SendSS provides individual child health and programmatic information for use by several Office of Birth Outcomes programs, Children 1<sup>st</sup>, UNHSI, NBS and HRIFU. The Coordinators of each program provides the subject matter expertise which is complemented by the epidemiological and statistical expertise of the

epidemiology staffs who assist in evaluating the effectiveness of each program's activities.

Since the Division was restructured, the GPHL and the GLPPP report to Dr. Lance, Director of the Protection and Safety Section. Morris Govan, Director of Operations, and Dr. Lance spearheaded a Division-wide initiative to perform a systems assessment of the NBS. Through this systems approach, meetings are convened with staff with oversight of the programs that either directly or indirectly impact the Division's ability to manage the NBS. To date, these meetings include Dr. Lance and Mr. Govan, the Directors of GPHL and Vital Records, Epidemiology Section (including the Birth Outcomes Unit epidemiologists and Health Information Systems staff) and Office of Birth Outcomes staffs (including the NBS) and budget analysts. The purpose of this assessment is to 1) define roles and responsibilities, 2) improve accountability for each Section's performance, 3) identify barriers and issues impacting each Section that plays a role in the Newborn Screening system, 4) improve communication across the Newborn Screening system and 5) work toward creating solutions to improve the efficiency and effectiveness of Newborn Screening. This initiative will continue through SFY 2008. The outcome should be a stronger relationship between the Newborn Screening Unit of GPHL, the NBS and the Birth Outcomes Epidemiology Unit. Meanwhile, each of these groups coordinates their efforts to ensure newborns screening specimens are collected and processed, analyze the results, monitor the data for quality assurance, detect and monitor the status of positive results, and ensure children with positive results are tracked to treatment.

The Vital Records Section and the Epidemiology Section have a strong working relationship. Representatives of each Section participate in weekly Division level meetings that monitor the success of the NBS. These meetings are a forum to identify areas for improvement, including the quality of the VEIS, NBS and SendSS data and the accuracy and completeness of

the probabilistic matching algorithms. In addition, Epidemiology staffs communicate regularly with the Vital Records Director to inform him about problems with the birth records and to obtain advice from lessons learned in implementing VEIS.

The Epidemiology Section also partners with the Georgia Chapter of the March of Dimes in the development and implementation of the GBDRIS. The GBDRIS staff works closely with the Georgia Folic Acid Task Force, a multi-disciplinary group comprised of individuals from the public and private sectors. Families, consumers and providers are represented on all Advisory Committees. Each committee meets regularly and receives updates on the status of SendSS. Northside Hospital, Georgia's largest birthing facility, is an important partner in the development and implementation of SendSS. Northside Hospital is piloting the interfaces for electronic reporting of hearing screening results and Children 1<sup>st</sup> referrals and will be the first hospital to use SendSS as its own hearing screening data management system.

## **PROGRAM CAPACITY**

The Division of Public Health is the lead agency responsible for the health of the people of Georgia. DPH is the designated state health agency, under the direction of Stuart Brown, M.D. with oversight over maternal and child health and children with special health care needs programs (e.g., HRSA Title V maternal and child health block grant activities, OPA Title X family planning programs, Part C of IDEA and CDC-funded immunization programs). DPH is also responsible for health monitoring activities (e.g., vital statistics, disease reporting, and health surveys). In January 2008, the Division was restructured and the Office of Birth Outcomes is now responsible for fulfilling the mandates of the federal and state programs under Title V, Title X and Part C of IDEA. The Vital Records, Epidemiology and Health Information Systems Sections all report to the Office of Epidemiology, Evaluation and Health Information.

The GLPPP and the GPHL report to the Office of Protection and Safety. All of these Offices, Sections, Units and supporting teams and programs have inter-relating responsibilities that require strong working relationships. More importantly, the Division's health information systems are consolidated under the Office of Epidemiology, Evaluation and Health Information. This will strengthen the Division's ability to integrate all child health information. See Appendices for an updated organizational chart.

UNHSI activities now fall under the Newborn Screening Program of the Office of Birth Outcomes and are more closely aligned with metabolic screening activities. UNHSI still plays a significant role within the broader child health framework. The following child health programs assure the capacity to implement and sustain the UNHSI program statewide, including: Children 1<sup>st</sup>, Babies Can't Wait; Children's Medical Services; perinatal hospital follow-up, and Health Check/Early Periodic Screening, Diagnosis and Treatment. Children 1<sup>st</sup> is Georgia's public health identification, referral and tracking process for infants and children under the age of five with various medical and social factors that place them at risk for poor health and developmental outcomes. BCW provides early intervention services to families whose infants are diagnosed with severe bilateral hearing loss and other developmental disabilities. Services are based on individual needs of the child and family and may include speech therapy, case management, parent support, and assistive technology. CMS provides financial assistance for specialty medical services including treatment, surgery, medication, hearing aids, and case management for income-eligible children with chronic medical conditions. Six designated, state-funded perinatal hospitals conduct follow-up clinics for high-risk infants to monitor development and make referrals to Children 1<sup>st</sup>, as well as offer technical assistance to other hospitals in their region regarding provision of services to high-risk pregnant women and infants. Health

Check/EPSTD offers a screening mechanism for identifying children with hearing impairment after birth and provides them with follow-up and referral services. The Office of Birth Outcomes oversees the planning, coordination, implementation, and evaluation of all these programs.

## **STAFFING AND MANAGEMENT SYSTEM**

The following DPH staffs are responsible for planning, implementing and monitoring the UNHSI process and SendSS statewide.

**John Horan, M.D. M.P.H.** Director, Epidemiology Section. Dr. Horan provides oversight for the infectious disease, chronic disease and maternal and child health epidemiology units. Dr. Horan will be the project director, in the interim, until a Birth Outcomes Unit Chief is hired.

**Chief, Birth Outcomes Unit.**, This position has been vacant since January 2008. A position was posted in February however a recent change to hiring processes has put management positions on-hold until reviewed by the Commissioner of DHR. When filled, this person will oversee this grant and the expansion of SendSS.

**Brendan Noggle, M.P.H.** Mr. Noggle is the Birth Outcomes Unit epidemiologist assigned to perform UNHSI surveillance analysis. His position will be funded under this grant. Mr. Noggle has assisted in the implementation of SendSS since May 2007. He will manage the deployment of SendSS, perform the system evaluation, and analyze epidemiologic and programmatic data.

**Jennifer Smith, M.P.H.** serves as the manager of the GBDRIS and is responsible for ensuring the goals and objectives of the GBDRIS are met. She is responsible for evaluating the data quality, developing statistical analyses and the preparation of reports.

**Newborn Screening Epidemiologist.** This position is currently vacant. When filled, this person will assist with data quality and reporting activities related to the Newborn Screening Program.

**Hui Zhang, M.D., M.P.H.** is responsible for linking MCH datasets with vital records. She is an

expert in both deterministic and probabilistic linking methods, and will be responsible for overseeing the data linkages and evaluation protocol for SendSS.

**Alexander Cowell**, Team Leader for SendSS, manages the SendSS Development Team. He is also the Acting Health Information Systems Section Chief. He will oversee the deployment and upgrades to SendSS, with assistance from Mr. Noggle.

**Daphne Terry Babrow, Ph.D., M.P.H., M.Ed.** is the Children 1<sup>st</sup> Program Manager. She manages the statewide Children 1<sup>st</sup> program and coordinates linkages with the CSN Programs.

**Sharon Quarry, M.S.** is the Team Leader, Newborn Screening Program. Ms. Quarry manages the statewide newborn screening program, including UNHSI, and coordinates the collection of all hearing screens, NBS data and genetics services.

## **EVALUATION PLAN**

Year 1 activities focus on training each type of end-user to access SendSS. Objectives 1.1, 1.2 and 1.3 will be measured using the following qualitative and quantitative outputs.

- a. Detailed plan for pilot implementation.
- b. Number and type of professional publications describing UNHSI process and purpose and use of SendSS Newborn.
- c. Number of regional and individualized training sessions held.
- d. Number and type of health care professionals trained to use SendSS.

A formal evaluation of the surveillance components of SendSS will be conducted in Year 2 using the CDC Guidelines for Evaluating Surveillance Systems<sup>2</sup>. Several of the objectives listed under goals 2 and 3 measure surveillance system attributes using qualitative and quantitative data. Measurable objectives and related activities are listed in the Work Plan matrix

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<sup>2</sup> Updated Guidelines for Evaluating Public Health Surveillance Systems, Recommendations from the Guidelines Working Group; July 27, 2001 / 50(RR13)

(see Appendix) with specific timelines incorporated for each activity. The Birth Outcomes Epidemiologist is responsible for conducting the system evaluation. He will convene a working group to assist in carrying out the activities necessary to conduct the evaluation as well as review the results and make recommendations for improvement. The working group will be comprised of representatives of the Health Information Systems and Epidemiology Sections, the Office of Birth Outcomes, one District Health Office, Northside Hospital, and at least one pediatric clinic, and audiologist. The evaluation will consist of the following:

- a. A detailed system evaluation plan with a concrete timeline.
- b. List of end-user participants to provide input through surveys and focus group formats.
- c. Surveys developed to assess simplicity, flexibility, acceptability and stability of system.
- d. System attributes will be assessed and analyzed through the following methods:
  - i. Pre-tested surveys will be distributed to a sample of each type of end-user (District, County, Hospital, Audiologist, Physician, State) to assess the simplicity, acceptability and flexibility of the system. Focus groups representing each type of end-user will also be convened to discuss barriers to reporting, potential modifications and methods to improve acceptance of the system.
  - ii. Data quality will be assessed routinely under Objectives 2.1 and 2.2. Children 1<sup>st</sup> and NBS have developed benchmarks to evaluate program performance. State-wide progress in meeting established benchmarks will be monitored on a routine basis. Indicators will be adjusted to complement changes to the work flow created by moving from paper-based reporting to a web-based system.
  - iii. Timeliness will be monitored through the Time frame analysis activities of Objective 2.2.

- iv. Completeness of UNHSI and NBS surveillance data will be analyzed routinely.
- v. Sensitivity and predictive value positive will be determined for hearing loss and at least one metabolic condition and one hemoglobinopathy. Specificity, sensitivity and predictive value positive will be evaluated for birth defects by comparing SendSS data to the gold standard, MACDP (Objective 3.1).
- vi. Representativeness will be analyzed through linkage of SendSS data with external data sets as described in Objectives 3.1 and 3.2.
- vii. Stability of SendSS will be assessed through focus group sessions with the SendSS Development Team as well as each type of end-user, an analysis of the technological infrastructure and logs of end-user system access over time.

The outcome of the evaluation will be documented in a final report describing each of the attributes analyzed and specific recommendations for improvement.

### **SUPPORT REQUESTED**

To complete the activities proposed in this grant application, funds to support one epidemiologist to provide surveillance evaluation and epidemiologic analysis of hearing loss using the UNHSI data collected through SendSS. This position will also serve as the day to day manager of SendSS, assuring the system is deployed statewide. Funds are also needed to hire one Support Analyst to provide training and help-desk support to end-users. This position will provide training through web-based interactive methods, as well as in classroom settings. Funds to support the licensure of Netrics, the probabilistic matching software used to match and link real-time records in SendSS, are also requested. A detailed, line item budget is provided in the attached Budget Justification.