

**CENTERS FOR DISEASE CONTROL AND PREVENTION  
CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES  
EARLY HEARING DETECTION AND INTERVENTION (EHDI) PROGRAM  
SITE VISIT REPORT– U.S. Virgin Islands  
April 29, 2004**

CDC Cooperative Agreement: UR3/CCU220040-02

Early Hearing Detection and Intervention Tracking Research and Integration with Other Newborn Screening Programs

Travelers

Marcus Gaffney, ORISE Fellow  
Pam Costa, Epidemiologist

Date and Location

March 25 - 26, 2004  
St. Thomas, U.S. Virgin Islands

Key Contacts in Attendance at Site Visit

Patricia Penn, MCH Director  
Darlene Carty, MA Ed, RTT, Commissioner of Health  
Jacquelyn Fredericks, Newborn Screening Technician  
Bernadine Williams, Data Entry Operator

**Significant Items Discussed**

*Organizational Structure*

The organization of the U.S. Virgin Islands Early Hearing Detection, Intervention and Tracking (EHDIT) project has remained the same since the last site visit in 2002. The program is located within the Division of Maternal and Child Health (MCH). The Part C Infants and Toddlers Program is also located within the Division of MCH.

*Legislation*

Currently there is no legislation related to infant hearing screening or other EHDIT activities in the U.S. Virgin Islands. Indications are that it will be unlikely for any EHDIT related legislation to be enacted in the near future. There is also no current legislation mandating blood spot screening.

*Funding and Grants*

The U.S. Virgin Islands was awarded a CDC Cooperative Agreement in July 2001. This Cooperative Agreement is scheduled to end in 2005. They do not have a Health Resources and Services Administration grant. The legislature does not provide funds for the EHDIT program. All costs related to newborn hearing screening are usually covered by MCH funds. Diagnostic evaluations and early intervention services for infants and children with hearing loss are usually provided at reduced or no cost through the Part C or MCH funds.

### *Advisory Committee*

An EHDI related advisory committee was established on both St. Thomas and St. Croix. Members include persons from the private and public sector, advocacy agencies, and family members of those with hearing loss. The committee continues to remain active and has been involved in drafting a sedation protocol for audiological testing and other related activities.

### *Screening and Referral Process*

The two birthing hospitals on St. Thomas and St. Croix are continuing to offer hearing screenings to the approximately 1700 newborns born each year. A hearing screening waiver form is now offered to parents if they wish to decline the no-cost screening. If an infant does not pass the first hearing screening, at least one additional screening is usually performed with the same technology before the infant is discharged. These screenings are conducted by designated part time Newborn Screening Technicians, which are funded by the EHDIT program. These technicians are also responsible for recording screening information on paper forms or logs, which are submitted to the EHDIT program and designated audiologists on a weekly basis. Despite the availability of funds, problems with retaining these screeners were noted and positions are currently open. Training and supervision of these technicians is technically the responsibility of the audiologist on each island, although it was noted that these functions are mostly performed by the audiologist on St. Croix.

The Juan F. Luis hospital on St. Croix has a room within the newborn nursery dedicated to performing hearing screenings. This room appears to be very conducive to performing screenings. There are also two screening (handheld OAE) units available at this hospital. Reports indicate the majority of infants born in this hospital receive a hearing screening before discharge. As on St. Thomas, results of the hearing screening continue to be recorded on an infant's Boy / Girl card. This card is typically taken by parents to the child's first doctor's appointment.

On St. Thomas, a room within the Roy L. Schneider hospital has been designated for the use of hearing screenings at set times during the week. Adjustments to this schedule are made in certain cases for outpatient screenings to help accommodate a parent's schedule. Screenings are also performed using a handheld OAE unit. As on St. Croix, this room appears conducive to testing. One of the Newborn Screening Technicians at this hospital, Jacquelyn Fredericks, has been performing hearing screenings since April 2002.

### *Diagnostic Audiologic Referral and Evaluation*

Parents of infants and children referred for follow-up testing are given an information packet about infant hearing loss and are asked to make an appointment for follow-up testing with the MCH / CSHCN audiologist. The Audiologist on each island also usually receives a list with the infants and children that require follow-up testing. As in the past, the screening technician is responsible for informing parents of the screening results in most cases.

As in 2002, there continue to be two audiologists who parents are usually referred to for their infant or child's follow-up testing. Wincess Gentius is on St. Croix and Mona Freeman is located at the clinic on St. Thomas. Infants from St. John that require follow-up testing are referred to the audiologist on St. Thomas. The audiologist on either island usually does another screening test before performing a diagnostic evaluation. Ms. Gentius visits St. Thomas to help reduce the number of infants awaiting follow-up testing. Both of the clinics where these audiologists are located have sound booths. There is a third audiologist on St. Croix who can be contracted through MCH to provide audiologic services when staff audiologists are unavailable. A sedation protocol, which has been requested by one of the audiologists has been drafted but not yet approved due to concerns by physicians that infants should only be sedated in a hospital setting as opposed to the clinics/offices where both audiologists are located. This delay has resulted in a list of infants who are waiting for recommended follow-up testing, which is considered a serious issue.

The audiology clinics/offices on both islands are equipped with various pieces of equipment to conduct screenings and diagnostic evaluations. On St. Croix a new Biologic ABR machine was recently purchased. However, insufficient training on the use of the machine was provided at the time of purchase and additional training is now needed. This has resulted in limited use of this ABR unit and has highlighted the immediate need for appropriate training to be arranged.

#### *Intervention Process*

If an infant or child is identified with a hearing loss (regardless of type and severity) audiologists are requested to send a referral report to the designated Part C coordinator within ten working days. Once this paperwork is received and processed the Part C program contacts the parents. Information about infants and children enrolled in intervention services is not formally reported on a regular basis to the EHDIT program, but it can reportedly be requested by the program. Physicians and parents may also refer infants and children to the Part C program.

The Part C program is funded through the Department of Education, but is administered through the Department of Health, Division of MCH. Intervention services for infants and children with a hearing loss are provided directly through Part C staff. A speech pathologist on St. Thomas and a speech therapist on St. Croix are available to provide these services. Hearing aids and cochlear implants (in some cases) are either paid for by the Part C program for children aged zero to three or by MCH for children older than three.

#### *Tracking and Surveillance System*

Hearing screening information is entered by hand into a module that was developed and incorporated into the existing Access database that is used to capture blood spot screening information. Hearing data to input into the database are obtained from the weekly logs that are submitted by each of the two birthing hospitals. Two separate versions of the hearing screening module/database are maintained: one on St. Croix and another on St. Thomas. Each of these databases includes only information for births on that respective island. At present, the information from both databases is not merged to create a dataset of all births in the U.S. Virgin Islands.

Since the last site visit in 2002 modifications were made by the database programmer, a private contractor located in Maryland, to enable the generation of reports. However these reports did not provide the individual and aggregate level information required by the program. The inability to generate reports was confirmed by CDC EHDI staff. During the site visit a teleconference was held that included the database programmer, the director of the EHDIT program, and CDC EHDI staff, which included a computer developer. During this teleconference the type of information and reports needed were reviewed. Following the site visit, the programmer began working in collaboration with a member of the CDC EHDI program to develop the required reports. Once this development is complete, the EHDIT program should be able to generate individual and aggregate level reports summarizing information (by month and year), such as the infants requiring follow-up testing and the total number screened for hearing loss. Availability of this information is anticipated to help increase the ability of the EHDIT program to ensure all infants and children receive recommended hearing related services.

#### *Integration of Data Systems*

Hearing related information is entered into a database that also houses blood spot screening data. As already noted, hearing screening and follow-up information for births on St. Croix and St. Thomas is housed in separate versions of the hearing screening module/database. Information from these two versions is not integrated. Indications are that an Electronic Birth Certificate will probably not be implemented in the near future.

## *Reimbursement / Payment Policies*

In-hospital hearing screenings are performed by Screening Technicians at no charge to parents or health insurers. Medicaid does not reimburse for hearing screenings. Part C typically pays for the majority of diagnostic evaluations and intervention services. Parents may be charged a percentage of the cost for these services depending on their level of income.

## *Other Notes*

A meeting was also held with the Health Commissioner, Darlene Carty. During this meeting the strengths of the EHDIT program were highlighted and issues such as the need for infants and children to receive timely follow-up testing were discussed. This included the need to finalize the aforementioned sedation protocols and the continuing staffing issues on St. Thomas.

## **Accomplishments, Future Directions and Recommendations**

### *Summary of Accomplishments:*

- Hearing screenings are performed on a regular basis in hospitals on both St. Croix and St. Thomas
- Infant hearing screening logs are now submitted to the EHDIT program office on a weekly basis
- Hearing screening results are consistently being entered into the newborn hearing screening database
- A standardized waiver for the refusal of hearing screening has been developed and is in use
- Additional newborns are being screened for hearing loss
- The Advisory Committee continues to be active in the development of guidelines and other related activities
- Newborn Screening Technicians are located in hospitals on both St. Croix and St. Thomas
- A packet with information about hearing screenings is distributed to parents
- A sedation protocol for follow-up testing has been drafted

### *Priority Areas for the Near Future:*

- Integrate databases from both St. Croix and St. Thomas so that only one copy is maintained which will include all hearing screening, and follow-up information for all infants born in the U.S. Virgin Islands.
  - If full integration is not possible merge information from the two databases on a regular basis
- Finalize and implement sedation protocol for conducting follow-up audiologic testing
- Obtain appropriate training for the ABR testing equipment located on St. Croix
- Ensure the newborn hearing screening database can generate appropriate aggregate and individual level reports (e.g., number of infants screened for hearing loss, infants requiring follow-up testing)
- Make back-up copies of the newborn hearing screening database on a regular basis (e.g., weekly or biweekly)
- Eliminate back-log of infants and children waiting for follow-up testing and diagnostic evaluations that appears to have resulted from audiology staffing issues on St. Thomas
- Ensure parents are receiving information about the need for follow-up testing from qualified individuals
- Continue efforts to finance the Screening Technicians after funding from the CDC EHDI Cooperative Agreement ends in year 2005
- Explore the possibility of further integrating with vital records

### *Comments and Recommendations:*

As noted during the last site visit, the Virgin Islands EHDIT program continues to appear to consist of a highly motivated and innovative group of individuals. The program has continued to make notable progress in the areas of screening and follow-up in spite of various challenges, including staffing issues. It is highly recommended that efforts be continued to further develop and integrate the hearing

screening database so that one version can include data for all births in the U.S. Virgin Islands. It is also recommended that efforts be continued to finalize and implement a sedation protocol and require if possible all staff to provide recommended follow-up testing in a timely manner.

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