

## Ongoing Research Projects With CDC-EHDI Funding

### Impact of Hearing Loss and Comorbidity on Virginia's Children and Families

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**Background:** Although in recent years states have made progress in the early identification of infants with hearing loss through their Early Hearing Detection and Intervention (EHDI) programs, it is estimated that as many as 40% of these children might have concomitant physical or developmental problems that could have an effect on delivery of services. Research studies of children with hearing loss typically have excluded those who present with additional health-related concerns. This project will gather much needed information about the experiences of infants and children with hearing loss who have coexisting congenital anomalies (HL/CCA) and their families (the target population).

**Purpose:** The purpose of the study is to develop a better understanding of how having a congenital anomaly can affect the identification, evaluation, and treatment of hearing loss. The information gained will be used to improve services and programs for the target population (children and their families). The project's goals are (1) to determine how comorbid congenital anomalies affect the identification, evaluation, and treatment of children with hearing loss, and (2) to assess the overall effect of a dual diagnosis of hearing loss and other congenital anomalies on each child and family.

**Methods:** The study will be conducted in two stages. During the first stage, the objectives of this study will be addressed by accessing and analyzing (1) a linked dataset containing data from the Virginia EHDI Program, the Virginia Congenital Anomalies Reporting and Education Systems (VaCARES), and vital records; (2) the results of a 2006 CDC-sponsored study of factors contributing to the loss of follow-up in the EHDI system; and (3) the results of a 2006–2007 Virginia Department of Health family satisfaction survey. During the second stage of the study, which is qualitative in nature, staff will conduct telephone-based parent interviews to identify challenges faced by families and to develop an in-depth understanding of the effect of having a child with HL/CCA.

**Current Status:** The names of families whose children met the criteria for inclusion have been retrieved. There were 266 confirmed cases of hearing loss. A research database of the VaCARES system data was created prior to migrating the data to a new system. Initial analysis of the 2005-2006 cohort of children has been completed. The protocol for the research study has been approved by VCU's IRB. Recruitment packets were assembled and mailed to the 266 families. Interviews with family members have been progressing well, and are providing information that will be very useful in assessing the impact of hearing loss and congenital anomalies on Virginia families and children. The process of data coding and analysis has begun. Proposal for a paper presentation has been submitted to the National EHDI conference in Dallas.