

## Ongoing Research Projects With CDC-EHDI Funding

### ***Loss to Follow-Up - CDC "1% Evaluation Project", CDC and RTI International***

Principal Investigator: Pam Costa- [pcosta@cdc.gov](mailto:pcosta@cdc.gov)

**Background:** To date, 38 states and the District of Columbia have implemented universal newborn hearing screening related legislation. It is estimated that as many as 90% or more of newborns in the United States are now screened for hearing loss. However, national data indicates that nearly half of newborns failing hearing screening tests do not return for one or more follow-up services (a hearing rescreen, audiometric evaluation, medical diagnosis, or intervention).

The value of newborn hearing screening cannot be realized unless children complete the evaluation process. Although CDC is now funding 30 jurisdictions to implement surveillance and tracking systems, there is no mechanism in place to determine why newborns do not return for rescreening, evaluation, diagnosis, or intervention (i.e., loss to follow-up).

**Purpose:** The intended use of the evaluation is to develop recommendations and activities that can be implemented by state Early Hearing Detection and Intervention or EHDI programs to reduce loss to follow-up. Additionally, states wishing to conduct their own evaluations will be able to use the survey tools developed for this project.

**Methods:** The contractor employed a variety of data collection tools, including focus groups, in-depth interviews, exit interviews, and a case control study of mothers. The analysis of the resulting data will identify barriers to completing the follow-up/evaluation components and strategies for improvement will be developed.

**Current Status:** Five states are participating in this study: Arkansas, Massachusetts, Michigan, Utah, and Virginia. Focus groups were completed in 2003-2004. Currently, mothers who have just given birth are completing a short written questionnaire before they leave the hospital, and mothers who have given birth within the past 6 to 18 months are completing telephone interviews. All data collection for this project is scheduled to be completed by December 2006, and the project is expected to be finished in 2007 (*Updated 10/2006*)