

Completed Research Projects With CDC-EHDI Funding

Family Surveys – Colorado Department of Public Health and Environment, Health Care Program for Children with Special Needs and Massachusetts Department of Public Health, Bureau of Family and Community Health

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Background: Approximately 1-3 infants per 1,000 infants are born with a congenital hearing loss. The Joint Committee on Infant Hearing and U.S. Department of Health and Human Services' Healthy People 2010 Objectives recommend that all newborns be screened for hearing loss by 1 month of age, have diagnostic follow-up by 3 months if the screening is positive, and receive appropriate intervention before 6 months of age if diagnosed with hearing loss. The U.S. Preventive Services Task Force has recommended that further research be conducted on the effects of newborn hearing screening processes on families.

Currently, there is no widely used survey instrument designed to collect data on parent satisfaction within a state EHDI program. Such a tool would allow for more complete evaluation of a state Early Hearing Detection and Intervention (EHDI) program and enhance the ability of the state to modify its program as needed based on user satisfaction.

Purpose: The purpose of this project was two fold: (1) to design survey instruments to evaluate their EHDI programs and to pilot them in two participating states, and (2) to evaluate parent satisfaction with the Colorado and Massachusetts EHDI programs. The goal of the project was to facilitate improvement of parent satisfaction within state EHDI programs

Methods: In this study, the two participating State Public Health Departments (Colorado and Massachusetts) surveyed parents regarding their experiences with and attitudes toward state EHDI systems. Families of infants in the EHDI system were recruited from each of three groups: (1) those whose infants passed the initial hearing screening; (2) those whose infants were referred from the first hearing screening, but passed the re-screen; and (3) those whose infants were identified with a permanent hearing loss through the state EHDI program.

Summary of Results: The tools were designed as mail surveys. Stakeholders, including parents of children with hearing loss, assisted the states in designing the three survey tools. The tools were translated into Spanish and the project design included oversampling of minority populations to facilitate responses from the diverse demographics of each state. Nearly 3,000 surveys were mailed, and the study achieved an approximately 25% response rate. The states are completing data analysis and will refine the survey tools based on feedback received from parents. The survey tools will then be made available to other states and territories. (Draft instruments are available on the CDC EHDI website: www.cdc.gov/ncbddd/ehdi/research.htm#evaluation). Preliminary results have been presented at a national EHDI conference. Publication of results is expected in the near future. (Updated 10/2006)