

FAMILY NOTIFICATION ANNOUNCEMENT

OPTION Schools, Inc. has developed a Listening and Spoken Language Data Repository (LSL-DR2) to advance the mission of OPTION Schools by establishing a national database of children and families who are attending or have attended a Listening and Spoken Language program. Currently there is no such national data base regarding outcomes in children with hearing impairment who use listening and spoken language. OPTION Schools will use the LSL-DR2 to collect, aggregate and summarize data from LSL programs to describe the population and to assess overall outcomes. Individual schools will use this program for quality monitoring of their schools. Specific information that will be collected in this national database will be annual speech-language-hearing information, type of technology used, and basic non-identifying demographic information.

The program that OPTION Schools has selected to store the data is REDCap (Research Electronic Data Capture) which is a secure, web-based application designed to support data capture for research studies which is supported at Vanderbilt Institute for Clinical and Translational Research (grant # 1 UL1 RR024975 from NCRR/NIH). If you have any questions about this project, please feel free to contact **Danielle Chalfant** at 217/326-2824 or the Principal Investigator of LSL-DR2, Tamala Bradham, Ph.D at 615-936-5267.

This system meets all security guidelines for web-based systems and is stored on the Vanderbilt server. **No personal identifying information is entered into the system.** Individual schools will have access only to the data that they upload into the LSL-DR2.

This letter serves as a notification to you about **Carle Auditory Oral School's** participation in this project. You may notify the director at your school if you wish for your child not to participate in this project. Choosing not to participate will have no effect on your child's placement or services at the school.

One goal of the LSL-DR project is to combine our children's outcomes with those of children enrolled in Listening and Spoken Language programs across the country to demonstrate that listening and spoken language is a viable communication option for children with hearing loss. We know that the services children receive through ECHO/ CAOS have changed lives and enabled children and families to return to their neighborhood schools to participate fully in their communities. But many people do not know about these outcomes. So many parents and professionals make the assumption that sign language is the only option for communication and education access once a hearing loss is diagnosed, and that children with hearing loss will lag behind their normally hearing peers in communication, social and academic skills. Your children's outcomes prove that it doesn't have to be that way.

The LSL-DR data base now contains outcome data on over 6,000 children with hearing loss who are enrolled in LSL programs across the country and are progressing in communication, social and academic areas because of those services. This large data set shows that children with hearing loss can advance in their communication, social interactions and academics, and can, on average, develop age appropriate skills in these areas.

Current research shows that individual child factors, such as the age they were first identified with hearing loss, family income level, and primary language spoken in the home impacts outcomes. But we also know that there are programs that are able to help children advance in their communication skills regardless of where children fall within these demographics. We want to be able to look at those programs that are successful with special populations and learn how they are supporting different groups of children so that our field as a whole can attain high outcomes for all of our students.

Toward that end, the next step of the project is to document demographic variables for each of the students in the data base and attempt to identify the impact of different variables. We hope to analyze the data and identify adaptations to our program to better engage and support children and families from a wider range of demographics and achieve even better outcomes for our students.

In order to do that, we are asking families to provide additional demographic data to help us in analyzing the factors impacting outcomes for our students. We are hopeful that each family will help us with this important project! The following information will be kept confidential and will be used only for the purposes of the LSL-DR project.

Please complete and turn in with the registration forms. Thank you for your time!

Child's Name: _____

Demographics

Child's Race: _____

Primary language spoken in the home: _____

Highest level of education completed - Mother: _____

Highest level of education completed - Father: _____

Hearing status since childhood - Mother: _____

Hearing status since childhood - Father: _____

Total number of children in the home: _____

Birth History

Pregnancy full term? _____

If not full term, how many weeks at delivery? _____

Hearing History

Child's age at diagnosis: _____

Child's age when fit with hearing aids: _____

Child's age when they first started services (speech, hearing or developmental therapy): _____

Child's age at first appointment with ECHO/CAOS: _____

Does your child have a known medical diagnosis related to the hearing loss? _____

If yes, what is the medical diagnosis? _____

Does your child have a known syndrome associated with the hearing loss? _____

If yes, what is the name of the syndrome? _____

Does your child have another disability, in addition to the hearing loss? _____

If yes, what is the name of the additional disability? _____

Services

Does your child receive services outside of ECHO/CAOS? _____

If yes, please describe services, frequency and duration of services: _____

Family Income Level (please check one)

Less than \$24,999

\$25,000 - \$49,999

\$50,000 - \$74,999

\$75,000 - \$99,999

Greater than \$100,000