

CAOS Family Notification Announcement

What is OPTION, Inc.?

OPTION is an international, non-profit organization of programs and schools for children who are deaf or hard of hearing learning to listen and talk. The organization advances the excellence in listening and spoken language education by providing information, engagement, and support to its member's programs. OPTION members educate the public, professionals, and policymakers as to what is possible for children who are deaf and hard of hearing in the 21st century.

What is LSL-DR?

OPTION developed the Listening and Spoken Language Data Repository (LSL-DR) in 2010. LSL-DR is an international database that contains non-identifying information on a child and their family's journey in developing spoken communication skills. Your child's program, **Carle Auditory Oral School**, is a member of OPTION. As part of the OPTION membership benefits, your child's program uses LSL-DR to store select data about your child's progress in developing listening and spoken language skills. LSL-DR does not store any protected health information.

What type of information is entered into the LSL-DR?

The type of information stored in LSL-DR is your child's annual speech-language-hearing information, type of technology used, services received, and non-identifying demographic information. The OPTION database does not contain any names, dates, or identification numbers that could be traced back to your child or family. Only your child's program can access your child's specific data. Since LSL-DR is a de-identifiable database, **no personal identifying information is entered into the database.** OPTION views the combined data from all the programs and does not know which data belongs to which child or family.

How does my child's intervention program and OPTION use the data entered into LSL-DR?

Your child's program reviews the data entered into LSL-DR to monitor the child's progress over time, assist with curriculum development, identify potential treatment goals, determine continuing education opportunities for their teachers and staff, and apply for grants that require outcome reporting. OPTION uses the data stored in LSL-DR to summarize data across all the programs to describe the population and overall outcomes and to learn about what factors contribute to a child's success.

Where is the data stored?

The computer software program that OPTION uses to store the de-identified data is REDCap (Research Electronic Data Capture). REDCap is a secure, web-based application designed to support data capture for research studies and is used all around the world. This system meets all security guidelines for web-based systems and is stored on the University of Miami server. This database has been reviewed by the University of Miami's Institutional Review Board.

Who do I talk with if I want more information about LSL-DR and my child's involvement?

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-DR, **Ivette Cejas, Ph.D.**, at icejas@med.miami.edu, or lsldr@optionschools.org.

Please note that unencrypted emails are not a secure or private means of communication. Email messages can be intercepted and read by others with access to your email account. Because of these risks, we recommend you avoid sending any health information or sensitive information via email unless encryption is used. However, the best means of communication is up to you.

This letter serves as a notification to you about **Carle Auditory Oral School's** participation in this project. You may notify Danielle Chalfant if you wish for your child's information not be stored in this database, LSL-DR. 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 who are deaf and hard of hearing. 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 who are deaf and hard of hearing will lag behind their typically 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 9,000 children who are deaf and hard of hearing 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 who are deaf and hard of hearing 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: _____ Date: _____

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