LSHSS

Research Note

The Listening and Spoken Language Data Repository: Design and Project Overview

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Purpose: The purpose of the Listening and Spoken Language Data Repository (LSL-DR) was to address a critical need for a systemwide outcome data–monitoring program for the development of listening and spoken language skills in highly specialized educational programs for children with hearing loss highlighted in Goal 3b of the 2007 Joint Committee on Infant Hearing position statement supplement.
Method: The LSL-DR is a multicenter, international data repository for recording and tracking the demographics and longitudinal outcomes achieved by children who have hearing loss who are enrolled in private, specialized programs focused on supporting listening and spoken language development. Since 2010, annual speech-language-hearing outcomes have been prospectively obtained by qualified clinicians and teachers across 48 programs in 4 countries.
Results: The LSL-DR has been successfully implemented, bringing together the data collection efforts of these programs to create a large and diverse data repository of 5,748 children with hearing loss.
Conclusion: Due to the size and diversity of the population, the range of assessments entered, and the demographic information collected, the LSL-DR will provide an unparalleled opportunity to examine the factors that influence the development of listening in spoken language in this population.

Hearing loss is considered a low incidence disability under the Individuals with Disabilities Education Act (2004), which, in turn, makes conducting and generalizing research a challenge. The U.S. Preventive Services Task Force further underscored this conclusion by reporting significant limitations in study designs, small sample sizes, and convenience samples in previously published research in the areas of pediatric identification of hearing loss and early intervention (Nelson, Bougatsos, & Nygren, 2008; U.S. Preventive Services Task Force, 2008). The Joint Committee on Infant Hearing (JCIH) has provided the current state of science and best practice guidelines for infants and toddlers at risk for or with identified hearing loss. In 2013, JCIH made 12 specific recommendations for early intervention services provided to children with hearing loss and their families. In particular, JCIH recommendations emphasized the need for appropriate access to services, utilizing service providers with knowledge and skills on the basis of current research, best practices, and proven models, and the development of a data system to monitor outcomes (JCIH, 2013).

Recognizing the need for systematic data collection and outcome monitoring of children with hearing loss who are enrolled in highly specialized educational programs, OPTION Schools, Inc. (OPTION) created the Listening and Spoken Language Data Repository (LSL-DR) to initiate and facilitate ongoing outcome data collection for children from birth to elementary school. OPTION is an international organization of private, not-for-profit schools and programs that provide listening and spoken language services and education for children with hearing loss and their families. The LSL-DR brings together the data collection efforts of these schools and programs to create a large and diverse data repository that can serve as a resource for examining auditory, speech, and language outcome data and the factors that may influence those outcomes. The purpose of this article is to provide an overview of the LSL-DR project by describing the project background, ethical considerations, and population characteristics of the first 5,748 children with hearing loss, from infancy to school age.

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OPTION Schools and Programs Background

Founded in 1980, OPTION's mission is to advance excellence in the listening and spoken language education by providing services that assist schools and programs to increase their effectiveness, efficiency, and ability to teach children to listen and talk. OPTION is committed to ensuring that children with hearing loss and their families have access to listening and spoken language education choices. OPTION is a coalition of programs that advances the listening and spoken language education by

- supporting and promoting educational options for children;
- measuring outcomes;
- establishing and sharing best practices; and
- raising awareness through advocacy.

OPTION membership eligibility requires that programs meet the following criteria:

- Espousal of the philosophy of the listening and spoken language education.
- Operated programs for children with hearing loss in an exclusively listening and spoken language environment.
- Approved, licensed, or accredited by a recognized agency and have been in operation for at least 3 years.
- Sponsored by another OPTION program for membership.

The children enrolled in these programs range from newborns to school-aged students; they have individualized education plans/individualized family service plans (IFSPs) developed through their Lead Early Intervention Agency/Local Educational Agency (LEA) or private program; and educational placement in an OPTION program was determined to be the least restrictive environment. For private placement, programs provided the family with an IFSP or individualized service plan as outlined in the Individuals with Disabilities Education Act (2004). Children remain in OPTION programs only as long as specialized services are needed. Once children demonstrate readiness for participation in an inclusive general education program and have met and sustained age-appropriate growth in spoken language skills and preacademic/academic readiness, they are transitioned to their LEA or private program of parental choice (e.g., day care, local school). Children may leave these member programs at any time for a variety of other reasons as well, including, but not limited to, parental choice, relocation, and service needs outside the scope of practice or the mission of the program. Although all programs provide services for preschool-aged children, the services provided at each program vary. Most programs provide early intervention services for children from birth to age 3 years. Some programs provide elementary and middle school classroom settings. Onsite audiology, speech-language pathology, occupational therapy, and/or music therapy are available at some programs, whereas others rely on outside agencies and providers for such services. Funding for OPTION programs also varies by location. Programs receive financial support through their LEA, grants and contracts, tuition payments by families, endowments, and/or philanthropic support.

Data Repository Project Overview

Following the JCIH (2007) call to action, in 2008, the OPTION Executive Board approved the development of an international repository of demographic and assessment data for children with hearing loss who are enrolled in OPTION educational programs that specialize in teaching children to use listening and spoken language. An OPTION task force was convened to review existing, peer-reviewed literature on outcomes in children with hearing loss who are developing listening and spoken communication. Generalizability of the current body of research was limited by small sample sizes, single-center design, and the absence of predictive variables. In addition, much of the published research was descriptive by design. Based on this review, the task force made recommendations on specific diagnostic information, demographic variables, and assessment data to characterize and prospectively track the development of children with hearing loss while enrolled in these programs. The goals of the data repository project established by OPTION's board and members were to

- create and maintain a robust source of longitudinal educational outcome data on children with hearing loss who are enrolled in specialized programs designed to help children develop listening and spoken communication;
- enrich a collaborative partnership with other similar programs, aimed at increasing the quality and application of educational data for program improvement purposes, highlighting effective practices, and maximizing child spoken language outcomes; and
- conduct and translate research to inform decision making and improve educational and therapeutic service delivery for children with hearing loss and their families.

OPTION, through a contract with an independent party, Vanderbilt University Medical Center (VUMC), brings together the data collection efforts of these programs to create a large and diverse data repository, the LSL-DR, that serves as a resource for examining auditory, speech, and language outcome data and the factors that may influence those outcomes. In addition to allowing for analyses of aggregated data, the LSL-DR was designed to provide individual member programs with access to their own local outcome data for monitoring children's progress, conducting program evaluation, implementing quality improvement, and disseminating outcomes to funding sources and policy makers.

Potential barriers identified during the development phase of the LSL-DR included the following: (a) security and confidentiality of data shared, (b) usage of the data, (c) standard of care in assessment practices across the member programs, and (d) time to implement tests and enter data into a repository. To set appropriate expectations and guidelines for data storage and usage, a data use agreement between participating programs and OPTION was obtained. The data use agreement clearly outlines all elements of the LSL-DR rules, security, ownership, and usage of the data. OPTION contracts with VUMC for the purposes of project oversight, training, data collection, and data analytics. External advisors serve to provide strategic guidance to OPTION and its members. The LSL-DR and associated research projects have been approved by the VUMC Institutional Review Board since 2009. Families of children enrolled in OPTION programs are notified of their program's participation in the project. The family notification letters, also approved by the VUMC Institutional Review Board, are available to families in eight languages, with additional translation planned as needed. Funding for the data repository came from membership dues and private foundations' support.

For data storage, the LSL-DR project selected Research Electronic Data Capture (REDCap), an electronic data capture tool hosted at Vanderbilt University (Harris et al., 2009). REDCap is a secure, web-based application designed to support data capture for research studies, providing (a) an intuitive interface for validated data entry, (b) audit trails for tracking data manipulation and export procedures, (c) automated export procedures for seamless data downloads to common statistical packages, and (d) procedures for importing data from external sources (Harris et al., 2009).

In order to maintain privacy, the LSL-DR project does not collect any of the following 18 identified sources of protected health information on the children entered into the repository: names, geographic subdivision smaller than a state, ZIP codes, dates, ages over 89 years, telephone numbers, fax numbers, e-mail addresses, social security numbers, medical record numbers, health plan beneficiary numbers, account numbers, certificate and license numbers, vehicle identification and serial numbers, license plate numbers, device identifiers and serial numbers, Internet URLs, computer Internet protocol addresses, biometric identifiers (finger and voice prints), full face photos and comparable images, and/or any other unique identifiers or codes. For purposes of confidentiality, the LSL-DR is a de-identifiable database, and participating programs are required to use and track identification numbers for current and longitudinal data entries. At this time, the LSL-DR contains over 1,900 unique de-identified data elements per child per year.

Measures Selection

In order to select and standardize measures to be entered into the LSL-DR, a survey was administered to participating programs to gather information about the assessments that were routinely administered in their programs. The survey revealed 66 different tests and measures that programs were using to track children's progress. Each of these measures was subjected to a comprehensive review of validity, reliability, scoring methods, strengths, and concerns. Based on this review, OPTION selected standardized measures in five language learning domains to be assessed annually. These measures assess receptive language, expressive language, receptive vocabulary, expressive vocabulary, and articulation (published in Bradham & Houston, 2015). In addition to these measures chosen for annual assessment and data entry by all programs, the LSL-DR database was designed to allow programs to enter and track results from other optional measures of specific relevance to their programs. Once the measures were selected, it took programs an average of 3 years to fully implement the standardized test battery due to training needs, obtaining funding necessary to purchase the assessments and protocol booklets, educating families, and incorporating assessments and data entry into standard of care and existing work flow.

Four norm-referenced tests are required each year, one test in each of the following five learning domains. Choice of test or tests within each category are based on state or local school district requirements, collaborating agency assessment protocols, and the utility of each measure for the development and monitoring of IFSP/individualized education plan goals specific to each child or student:

- Expressive and receptive language
  - Clinical Evaluation of Language Fundamentals Preschool–Fourth or Fifth Editions (Semel, Wiig, & Secord, 2003; Wiig, Secord, & Semel, 2004);
  - Oral and Written Language Scales–Second Edition (Carrow-Woolfolk, 2011); or
  - Preschool Language Scale (Zimmerman, Steiner, & Pond, 2011).
- Expressive vocabulary
  - Expressive Vocabulary Test (EVT; Williams, 2007) or
  - Expressive One-Word Picture Vocabulary Test (EOWPVT; Brownell, 2010a).
- Receptive vocabulary
  - Peabody Picture Vocabulary Test (PPVT; Dunn & Dunn, 2007) or
  - Receptive One-Word Picture Vocabulary Test (ROWPVT; Brownell, 2010b).
- Articulation
  - Goldman-Fristoe Test of Articulation (Goldman & Fristoe, 2000) and
  - Arizona Articulation Proficiency Scale (Fudala, 2000).

In addition to these required measures, the LSL-DR currently allows programs to enter data from more than

90 optional measures. These measures assess language development, expressive and receptive vocabulary, auditory and speech perception, articulation, literacy development, school readiness, child development, and cognition.

Programs also collect three functional outcome measures that were developed by OPTION to track functional use of audition, expressive language, and receptive language. These measures are similar to the Functional Communication Measures by the National Outcomes Measurement System (NOMS) of the American Speech-Language-Hearing Association (ASHA; Gallagher, Swigert, Baum, 1998; Mullen & Schooling, 2010). The ASHA NOMS Functional Communication Measures are scored by a speech-language pathologist on admission and again at discharge from services in order to document the amount of change in communication and/or swallowing abilities after intervention. NOMS is reserved for only certified speech-language pathologists and members of ASHA. The speech-language pathologists must also complete required training before submitting data to NOMS. Because children with hearing loss are served by a variety of professionals (i.e., teachers of the deaf and hard of hearing, audiologists, LSL-certified professionals, and/or speech-language pathologists) and NOMS did not include an auditory measure, OPTION created three specific functional outcome measures to monitor the progress of the children enrolled in their programs to be used on an annual basis. The levels for the functional measures were determined by a consensus of an expert panel of audiologists, speech-language pathologists, and teachers of the deaf and hard of hearing on the basis of successive improvement stages. Like NOMS, the OPTION functional measures used a 7-point rating scale (see Table 1). The levels on the OPTION functional outcome measures represent typical successive stages of improvement. The service providers and teachers each individually rate the children that they serve based on 90% mastery at the corresponding level. Level 1 represents minimal behaviors observed to Level 7 representing advanced and robust demonstration of behaviors. It is recommended that all professionals working with a child complete the functional outcome measures. When there is a discrepancy in the individual ratings among the professionals, the team convenes to discuss the rating and reach a consensus on the appropriate level to report. This method was selected to reduce individual bias effects (Gorse & Sansderson, 2007).

Data Collection and Entry

To date, 48 educational programs have collected and entered de-identified data on demographic characteristics, service provision, audiologic status, and auditory, speech, language, and academic performance on norm- and criterion-referenced tests across the time span that the children have been enrolled in these highly specialized intervention programs (see Table 2). Each program is required to identify at least two staff members who are responsible for data entry and reporting. In order to have access to the LSL-DR, individuals are required to attend a live, virtual 1.5-hr training session on project objectives, procedures, and data entry. Individuals are assigned to data access groups on the basis of their assigned program. While the trained LSL-DR users can add, edit, and export their site-specific data, they are not able to view or export other data entries from other schools or programs. Approximately one hundred fifty individuals have access to program-site data across the programs at any given time. Programs have been entering data prospectively since November 10, 2010.

To assist programs with data entry, OPTION has provided small, need-based grants to the member programs to help support LSL-DR initiatives. On average, the data entry time ranges from 20 min to 60 min for each child. Due to the multidisciplinary assessment and management of children with hearing loss, obtaining records from outside practices and agencies has been identified as a major obstacle in data collection and entry. As reported by member school and programs, many audiology providers do not routinely administer speech perception measures or unaided audiometric testing in children with cochlear implants and/or share audiometric findings with the educational programs. Additionally, in order to ensure validity of the assessment results and to avoid duplicating assessments within the recommended test–retest time frame, member programs must coordinate the time frame for their own test administration with any external professionals or multidisciplinary team members.

Summary of Population Characteristics

The analyses presented here aim to describe the variety of data held within the LSL-DR, its quality, and its relevance to a broad range of health services research in children with hearing loss enrolled in highly specialized listening and spoken language programs. They provide information on representativeness of the population characteristics, quality in terms of missing data rates, and an analysis technique for creating a common scale for learning domains.

Population characteristics were calculated on the first 5,748 children with hearing loss entered into the LSL-DR. Each child appears in the data set once in Tables 3, 4, and 5. Due to the nature of a data repository, not all data were collected by each program at the initiation of the repository. Thus, all percentages were calculated based on nonmissing values. This is further portioned by type of hearing loss, degree of hearing loss, technology, and educational placement and services. More than half of the participants in the data repository are full-term, white boys who predominantly speak English at home. Approximately 30% have identified causes for their hearing loss. Furthermore, 75% of the children have no reported additional disabilities as diagnosed by a physician (see Table 3). Almost a third of the children have bilateral profound hearing loss (31%) and wear bilateral hearing aids (47%; see Table 4). For the past 3 academic years, more than half of the children received services exclusively at an OPTION program (see Table 5). More than a third of the children with hearing loss in classroom settings were co-enrolled with children

Table 1. Functional outcome measures.

Functional level	Auditory	Expressive language	Receptive language
1	The child does not respond to sound, neither environmental sounds nor spoken language.	The child attempts to speak, but vocalizations are not meaningful to familiar or unfamiliar communication partners at any time.	The child is alert but unable to follow simple directions or respond to yes/no questions, even with prompts.
2	The child has developed an awareness of sound used within a close proximity.	The child attempts to speak, although few attempts are accurate or appropriate. The communication partner must assume responsibility for structuring the communication exchange and, with consistent and maximal prompting, the child can only occasionally produce automatic and/or imitative words and phrases, which are rarely meaningful in context.	With consistent cues and prompts, the child is able to follow simple verbal directions, respond to simple yes/no questions in context, and respond to simple words or phrases related to the child's needs.
3	The child demonstrates consistent discrimination of prosodic and suprasegmental aspects of spoken language during informal and formal learning interactions within educational, vocational, and social situations.	The communication partner must assume responsibility for structuring the communication exchange. With consistent and moderate prompting, the child can produce words and phrases that are appropriate and meaningful in context.	The child usually responds accurately to simple yes/no questions. The child is able to follow verbal simple directions out of context with prompting. Accurate comprehension of more complex verbal directions is minimal.
4	The child demonstrates inconsistent closed-set word and short phrases identification during informal and formal interactions within educational, vocational, and social situations.	The child is successfully able to initiate communication using spoken language in simple, structured conversations in routine daily activities with familiar communication partners. The child usually requires moderate prompting but is able to demonstrate simple sentences.	The child consistently responds accurately to yes/no questions and occasionally follows simple directions without prompts. Moderate verbal contextual support is needed to understand complex verbal sentences. The child is able to understand limited conversations about routine daily activities with familiar communication partners through audition.
5	The child is successfully able to identify words varying in vowel and consonant content during informal and formal interactions within educational, vocational, and social situations.	The child is successfully able to initiate communication using spoken language in structured conversations with both familiar and unfamiliar communication partners. The child occasionally requires minimal prompting to frame more complex sentences in messages.	The child is able to understand spoken communication in structured conversations with both familiar and unfamiliar communication partners. The child occasionally requires minimal prompting to understand more complex sentences. The child occasionally initiates the use of compensatory strategies when encountering difficulty.
6	The child is successfully able to follow conversations of an undisclosed topic during informal and formal interactions within educational, vocational, and social situations.	The child is successfully able to communicate in most activities, but some limitations in spoken language are still apparent in educational, vocational, or social activities. The child rarely requires minimal prompting to frame complex sentences.	The child is able to understand verbal communication in most activities, but some limitations in comprehension are still apparent in educational, vocational, or social activities. The child rarely requires minimal prompting to understand complex sentences. The child usually uses compensatory strategies when encountering difficulty.
7	The child is successfully able to process information while listening with competing stimuli during informal and formal interactions within educational, vocational, and social situations.	The child is able to successfully and independently participate in educational, vocational, and social activities, which are not limited by spoken language skills.	The child is able to independently participate in educational, vocational, and social activities, which are not limited by spoken language comprehension. When difficulty with comprehension occurs, the child consistently uses a compensatory strategy.

Table 2. Participating OPTION member schools and programs that have contributed to the LSL-DR.

Name	City	State/County/ Providence	Country
Atlanta Speech School–Katherine Hamm School	Atlanta	Georgia	United States of America
Auditory Oral School of San Francisco	San Francisco	California	United States of America
Buffalo Hearing and Speech Center	Buffalo	New York	United States of America
Carle Auditory Oral School	Urbana	Illinois	United States of America
CCHAT Center–Sacramento	Sacramento	California	United States of America
Center for Hearing and Speech	Houston	Texas	United States of America
Central Institute for the Deaf	St. Louis	Missouri	United States of America
Child's Voice	Wood Dale	Illinois	United States of America
Children's Hearing & Speech Centre of British Columbia	Vancouver	British Columbia	Canada
Clarke Schools for Hearing and Speech, Jacksonville	Jacksonville	Florida	United States of America
Clarke Schools for Hearing and Speech, New York	New York	New York	United States of America
Clarke Schools for Hearing and Speech, Philadelphia	Philadelphia	Pennsylvania	United States of America
Clarke Schools for Hearing and Speech, Boston	Canton	Massachusetts	United States of America
Clarke Schools for Hearing and Speech, Northampton	Northampton	Massachusetts	United States of America
DePaul School for Hearing and Speech	Pittsburgh	Pennsylvania	United States of America
Desert Voices	Phoenix	Arizona	United States of America
Hear ME Now!	New Gloucester	Maine	United States of America
Hearing School of the Southwest	Coppell	Texas	United States of America
Hearts for Hearing	Oklahoma City	Oklahoma	United States of America
HOPE Oral Program of Excellence	Spokane	Washington	United States of America
Instituto Oral Modelo	Buenos Aires	–	Argentina
John Tracy Clinic	Los Angeles	California	United States of America
Lexington Hearing and Speech Center	Lexington	Kentucky	United States of America
Listen and Talk	Seattle	Washington	United States of America
Magnolia Speech School	Jackson	Mississippi	United States of America
Mama Lere Hearing School at Vanderbilt	Nashville	Tennessee	United States of America
Memphis Oral School for the Deaf	Memphis	Tennessee	United States of America
Montreal Oral School for the Deaf	Westmount	Quebec	Canada
Moog Center for Deaf Education	St. Louis	Missouri	United States of America
Moog School at Columbia	Columbia	Missouri	United States of America
New Orleans Oral School	Metairie	Louisiana	United States of America
Northern Voices	Roseville	Minnesota	United States of America
Ohio Valley Voices	Loveland	Ohio	United States of America
Oralingua School for the Hearing Impaired	Whittier	California	United States of America
Presbyterian Ear Institute	Albuquerque	New Mexico	United States of America
Sound Beginnings of Cache Valley	Logan	Utah	United States of America
St. Joseph Institute for the Deaf, Indianapolis	Indianapolis	Indiana	United States of America
St. Joseph Institute for the Deaf, Kansas City	Kansas City	Kansas	United States of America
St. Joseph Institute for the Deaf, St. Louis	Brentwood	Missouri	United States of America
Strivright	Brooklyn	New York	United States of America
Summit Speech School	New Providence	New Jersey	United States of America
Sunshine Cottage School for Deaf Children	San Antonio	Texas	United States of America
The Children's Cochlear Implant Center at University of North Carolina	Chapel Hill/Durham	North Carolina	United States of America
The Elizabeth Foundation for Deaf Children	Portsmouth	Hampshire	England
The Omaha Hearing School for Children	Omaha	Nebraska	United States of America
Tucker Maxon School	Portland	Oregon	United States of America
University of Miami Debbie Institute	Miami	Florida	United States of America
Weingarten Children's Center	Redwood City	California	United States of America

Note. OPTION = OPTION Schools, Inc.; LSL-DR = Listening and Spoken Language Data Repository; CCHAT = Children's Choice for Hearing and Talking.

Table 3. Population characteristics of children with hearing loss who are entered in LSL-DR (N = 5,748).

Parameters	*N* (%)
Sex	
Male	2,915 (52)
Female	2,702 (48)
Missing	131 (2.3)
Race	
White	2,830 (51)
Black or African American	559 (10)
Hispanic or Latino	1,090 (20)
Asian	460 (8)
Native Hawaiians/Pacific Islanders	25 (< 1)
American Indian/Native Alaskan	19 (< 1)
Multiracial	298 (5)
Unknown	120 (2)
Other	183 (3)
Missing	164 (2.9)
Primary language spoken in home	
English	4,405 (79)
Spanish	598 (11)
Mandarin	111 (2)
French	34 (1)
German	3 (< 1)
Tagalog	10 (< 1)
Other	392 (7)
Missing	195 (3.4)
Week's gestation	
≥ 36 weeks	4,015 (74)
< 36 weeks	625 (11)
Unknown	804 (15)
Missing	304 (5)
Known cause of hearing loss identified	
Yes	1,701 (31)
No	2,741 (49)
Suspected, but not identified	284 (5)
Unknown	816 (15)
Missing	206 (4)
Known syndrome identified	
Yes	494 (9)
No	4,435 (80)
Suspected, but not diagnosed	121 (2)
Unknown	471 (9)
Missing	227 (4)
Additional diagnosed disability	
Yes	739 (13)
No	4,135 (75)
Suspected, but not diagnosed	233 (4)
Unknown	425 (8)
Missing	216 (4)
Subjective rating of concerns identified on the child's ability to learn[a]	
No concerns	1,140 (24)
Mild concerns	458 (10)
Moderate concerns	501 (10)
Severe concerns	325 (7)
Not applicable, no additional disabilities suspected or identified	2,420 (50)
Missing	904 (16)
Parental hearing status[a]	
Both parents do not have hearing loss	4,010 (79)
Both parents have hearing loss	58 (1)
Mother has hearing loss	141 (3)
Father has hearing loss	95 (2)
Unknown	779 (15)
Missing	665 (12)
Number of children in home	
1	1,540 (28)
2	2,103 (38)
3	960 (17)
4 or more	579 (11)
Unknown	338 (6)
Missing	228 (4)
Mother's educational level[a]	
Eighth grade or less	87 (2)
Some high school	204 (4)
High school diploma/GED[b]	635 (11.5)
Some college	791 (14)
Bachelor's degree	1,187 (21.5)
Postgraduate degree	661 (12)
Unknown	1,951 (35)
Missing	232 (4)
Father's educational level[a]	
Eighth grade or less	84 (2)
Some high school	209 (4)
High school diploma/GED[b]	694 (12)
Some college	620 (11)
Bachelor's degree	966 (18)
Postgraduate degree	650 (12)
Unknown	2,286 (41)
Missing	239 (4)
Family involvement at initial assessment	
Ideal participation	1,278 (32)
Good participation	1,198 (30)
Average participation	1,028 (26)
Below average participation	351 (9)
Limited participation	108 (3)
Missing	1,785 (31)

Note. LSL-DR = Listening and Spoken Language Data Repository.
[a]New variable as of January 7, 2013. [b]General equivalency diploma.

without hearing loss who are typically developing. Since academic year 2013–2014, the number of children enrolled in early intervention has increased, whereas the number of children enrolled in preschool and school has decreased (see Table 5).

Based on the functional outcome measures completed on children with hearing loss between birth and 5 years 11 months of age, approximately two thirds of the children made at least one level change from the prior year in each functional domain (see Figure 1). These findings are consistent with ASHA's NOMS Spoken Language Comprehension and NOMS Spoken Language Production for Pre-Kindergarten (ASHA, 2011; see Table 6).

Figure 2 presents the percentage of children with hearing loss by age for each functional level. As expected, on the basis of their ages and typical patterns of language development, children with hearing loss between the ages of birth and 2 years tended to score at Level 1 or 2, whereas children with hearing loss between the ages of 4 and 5 years scored at higher functional measures, Level 5, 6, or 7. More than half of the children with hearing loss scored at a functional Level 4 or greater in audition (77%), comprehension (51%), and expression (52%) by age 3 years.

Table 4. Type, degree, and technology utilized by children who are deaf and hard of hearing (*N* = 5,748).

Parameters	*N* (%)
Type of hearing loss	
Bilateral	
Sensorineural	3,751 (74)
Auditory neuropathy	179 (4)
Mixed	140 (3)
Conductive	209 (4)
Normal	14 (< 1)
Unknown	64 (1)
Unilateral	
Sensorineural	330 (6)
Auditory neuropathy	23 (< 1)
Mixed	27 (1)
Conductive	195 (4)
Unknown	20 (< 1)
Asymmetrical	146 (3)
Missing	650 (11)
Degree of hearing loss	
Bilateral	
Normal (< 15 dB HL)	18 (< 1)
Slight (15–25 dB HL)	38 (< 1)
Mild (26–40 dB HL)	337 (7)
Moderate (41–55 dB HL)	544 (11)
Moderately severe (56–70 dB HL)	410 (8)
Severe (71–90 dB HL)	331 (7)
Profound (> 90 dB HL)	1,559 (31)
Unilateral	
Slight (15–25 dB HL)	18 (< 1)
Mild (26–40 dB HL)	57 (1)
Moderate (41–55 dB HL)	124 (2)
Moderately severe (56–70 dB HL)	143 (3)
Severe (71–90 dB HL)	93 (2)
Profound (> 90 dB HL)	106 (2)
Asymmetrical	1,308 (26)
Missing	662 (12)
Technology at initial assessment	
No technology	454 (9)
Bilateral	
Hearing aids	2,433 (47)
Cochlear implants	1,017 (20)
Softband BAHD	77 (1)
Hearing aid and Cochlear implant (bimodal)	405 (8)
Other	4 (< 1)
Unilateral (technology in only one ear)	
Hearing aids	273 (5)
Cochlear implants	237 (5)
Softband BAHD	220 (4)
Other	16 (< 1)
Other technologies	27 (1)
Missing	585 (10)

Note. BAHD = bone anchored hearing device.

Learning Domains Analysis

Because programs had a choice of two to three tests within each learning domain, it was necessary to determine the feasibility of developing a common scale for each domain. We compared standard scores within learning domains and found a strong linear correlation between tests (see Figure 3), with a coefficient of determination of more than .8 for each relationship. Therefore, we fit linear models, via ordinary least squares, to map scores onto a common scale for each learning domain. Within each learning domain, the most prevalent test was used as the baseline measure. This baseline measure was then projected onto the other administered test(s) using a common scale. Pairs of scores were chosen from all individuals who had scores for two domain tests, taken during the same age interval. For articulation, the Arizona Articulation Proficiency Scale was projected to the Goldman-Fristoe of Articulation scale; for receptive vocabulary, the PPVT was projected to the ROWPVT; for expressive vocabulary, the EVT was projected to the EOWPVT; for expressive and receptive language, all tests were projected to the Preschool Language Scale. For each projection, a univariate linear regression was fit

$$score_i^{(to)} = \beta_0 + \beta_1 score_i^{(from)} + \in_i, \quad (1)$$

where $score^{(to)}$ is the measure that was used as the target of the conversion, $score^{(from)}$ is the score being converted, β_i are regression covariates, and $\in$ is the normally distributed process error. Model coefficient of determination values (R^2) among the models ranged from .60 to .76.

For all of the standardized measures included in the LSL-DR, the average range for children with typical hearing is a standard score of 85 to 115 (100 ± 1 *SD*). Distributions of standard scores for the five learning domains are presented in Figure 4 for children with hearing loss at ages 3, 4, and 5 years. These overall outcome measures include all enrolled children within the 3- to 5-year age range. Overall, the 3-, 4-, and 5-year-old scores were very similar across the language learning domains.

Because the distribution of standardized test scores was quite similar across the three age groups, we pooled the scores for each language learning domain for each age group, as shown in Figure 5. Figure 5 shows the distributions of standardized test scores across language learning domains, pooled across ages. Boxes represent the interquartile range, whereas the whiskers delineate the 2.5 and 97.5 percentiles of the distribution. Individual student scores are overplotted with gray points. Individual students may appear multiple times if they recorded test scores two or more times in a given year.

Discussion

The overarching goals of the LSL-DR project were to create a system for data collection, analysis, and sharing, to promote within- and across-program evidence-based practices and, ultimately, to disseminate findings to families, researchers, and policy makers. This research note aimed to describe progress made in reaching these goals and to share lessons learned. With almost a decade of experience in designing an infrastructure to develop, manage, and share findings, OPTION has created a robust source of longitudinal data on over 6,000 children with hearing loss. The ability to aggregate data across more than 40 programs helps to address the limitations of small sample sizes inherent in research with low incidence populations (Goal 1).

Table 5. Educational services of children with hearing loss who are entered in LSL-DR.

Educational/Intervention services	2013–2014	2014–2015	2015–2016
Count of children served	2,209	1,977	2,082
Intervention services[a]			
OPTION only	1,367 (68)	1,316 (69)	1,342 (65)
OPTION and other intervention services outside the OPTION program	637 (32)	600 (31)	721 (35)
Missing[b]	205 (9)	61 (3)	19 (< 1)
Classrooms[a]			
Classroom with only children with hearing loss	639 (58)	550 (51)	528 (56)
Classroom with children with hearing loss and typical developing children/typical hearing	411 (37)	484 (45)	407 (43)
Classroom with children with hearing loss and nontypical developing children	61 (6)	42 (4)	10 (1)
Missing[c]	160 (13)	69 (6)	106 (10)
Grade			
Early intervention	820 (39)	780 (41)	1,022 (49)
Three-year-old preschool	315 (15)	296 (15)	270 (13)
Four-year-old preschool	464 (22)	422 (22)	378 (18)
Kindergarten (on the basis of state guidelines)	155 (7)	178 (9)	155 (8)
First grade	75 (4)	89 (5)	88 (4)
Second grade	68 (3)	56 (3)	56 (3)
Third grade and higher	194 (10)	104 (5)	104 (5)
Missing[b]	118 (5)	52 (3)	9 (< 1)

Note. LSL-DR = Listening and Spoken Language Data Repository; OPTION = OPTION Schools, Inc.

[a]New variable as of January 7, 2013. [b]Percentage calculated based on count of children served. [c]Percentage calculated based on classroom grades excluding early intervention.

The creation of a large-scale, multisite data repository required assistance from multiple sources, including legal counsel for the development of data use agreements and contracts and ongoing support and advice from staff at member programs and collaborative research partners. In addition, the project has required the development of an infrastructure for project management and technical support, allocation of time at the individual program level, and acquisition of funding. In an environment where every dollar of expense is scrutinized in nonprofit organizations, the OPTION programs rose to the challenge of allocating staff time for training and data collection and entry in the LSL-DR. Commitment by member schools in creating a data collection system has led to more consistent annual assessment practices across programs. With the creation of the LSL-DR, programs have created efficient workflow

Figure 1. Functional outcome measures: proportions of children with hearing loss achieving no change, an increase in one level, or an increase in two or more levels from 1 year to the next in each learning domain.

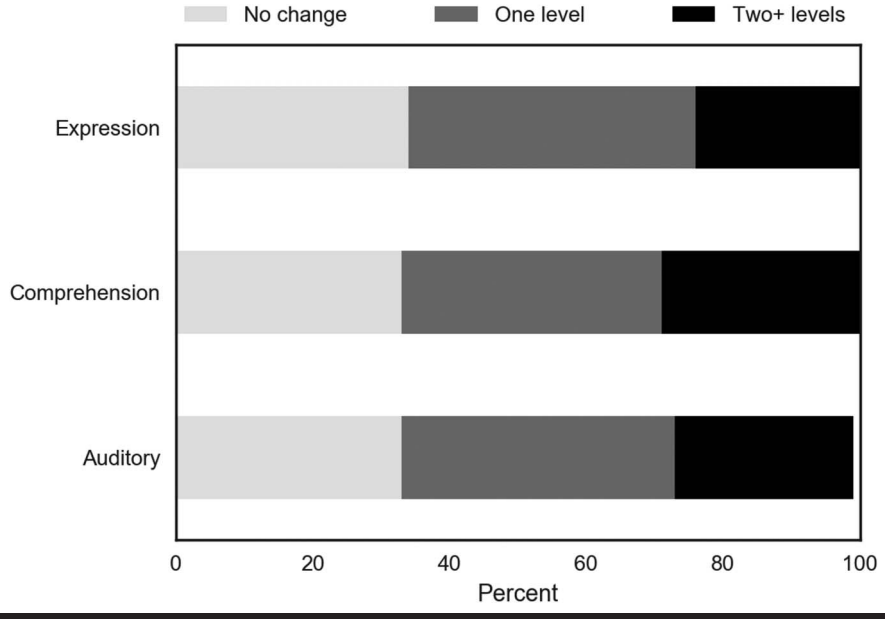


Table 6. Comparison of OPTION functional outcomes to the ASHA's NOMS (%).

	Expression		Comprehension	
Levels	**OPTION**	**ASHA**	**OPTION**	**ASHA**
No changes	34	32	33	35
One level change	42	39	38	39
Two or more levels change	24	28	29	26

Note. OPTION = OPTION Schools, Inc.; ASHA = American Speech-Language-Hearing Association; NOMS = National Outcomes Measurement System.

plans for data collection and now have centralized testing opportunities to allow for data sharing and collaboration. As of this publication, the cost for this data repository has been $403,493. This cost does not include the donated volunteer time of the many internal groups and committees and external advisors, costs of the tests and test forms, or data collection and entry time across the programs.

The second goal of the LSL-DR was to encourage schools to use their data to inform program improvement, highlight effective practices, and maximize child spoken language outcomes. Not only does the LSL-DR allow for analysis across programs, but it also allows individual programs to have their own database for program management and evaluation. Program administrators are able to generate reports through REDCap to review internal trends and to identify areas of strengths and opportunities for continuing education and peer mentoring. Programs, also, are able to monitor the children's progress over time by individual children or by cohorts. Readily available outcome information from the LSL-DR helps programs provide outcome data to parents, state and local agencies, donors, policy makers, and other key stakeholders.

The use of standardized tests, as well as functional measures in the LSL-DR, provides a means to quantify and track changes in the children's overall language and auditory development. Functional outcome measures, used throughout the child's intervention as part of periodic standard of care re-evaluations, provide information about whether predicted outcomes are being realized in everyday language use. In addition, functional outcome measures provide a common language with which to evaluate the success of specialized listening and spoken language interventions.

This research note is the starting point for addressing the third goal of the project—to conduct and translate research, to inform decision making, and to improve educational and therapeutic service delivery for children with hearing loss and their families. Reliable data supporting outcomes and effectiveness are especially critical in light of health care policy initiatives like Early Hearing Detection and Intervention Act of 2010 (Pub. L. No. 111–337) and education policy initiatives like Every Student Succeeds Act (2015; Pub. L. No. 114–95) in the United States. With the current expectation in the broader education and clinical practice fields focused on evidence-based practice and reimbursement on the basis of outcomes, parents and interventionists (including teachers, speech-language pathologists, and audiologists) need reliable data to make informed decisions regarding technologies, language intervention, and educational placement. The LSL-DR is now a potential resource to help address these matters.

To this end, current projects underway using the LSL-DR include the development of statistical models to help predict the trajectory of spoken communication and

Figure 2. Functional outcome measures: distribution of children with hearing loss among functional levels within each of the learning domains. Each line represents a distinct age group.

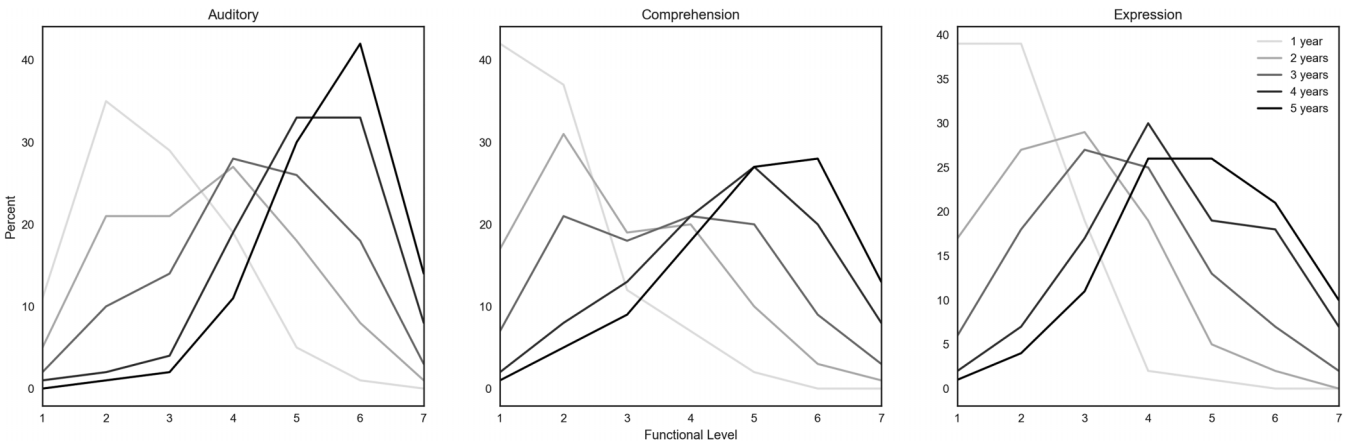


Figure 3. Scatterplot of test scores showing a strong linear relationship within the learning domains (a) articulation, (b) expressive vocabulary, and (c) receptive vocabulary. A hypothetical perfect relationship is shown with the dashed line, with the realized relationship represented as a locally weighted scatterplot smoothing (LOWESS) regression estimate with the solid line. EOWPVT = Expressive One Word Picture Vocabulary Test; EVT = Expressive Vocabulary Test; ROWPVT = Receptive One Word Picture Vocabulary Test; PPVT = Peabody Picture Vocabulary Test.

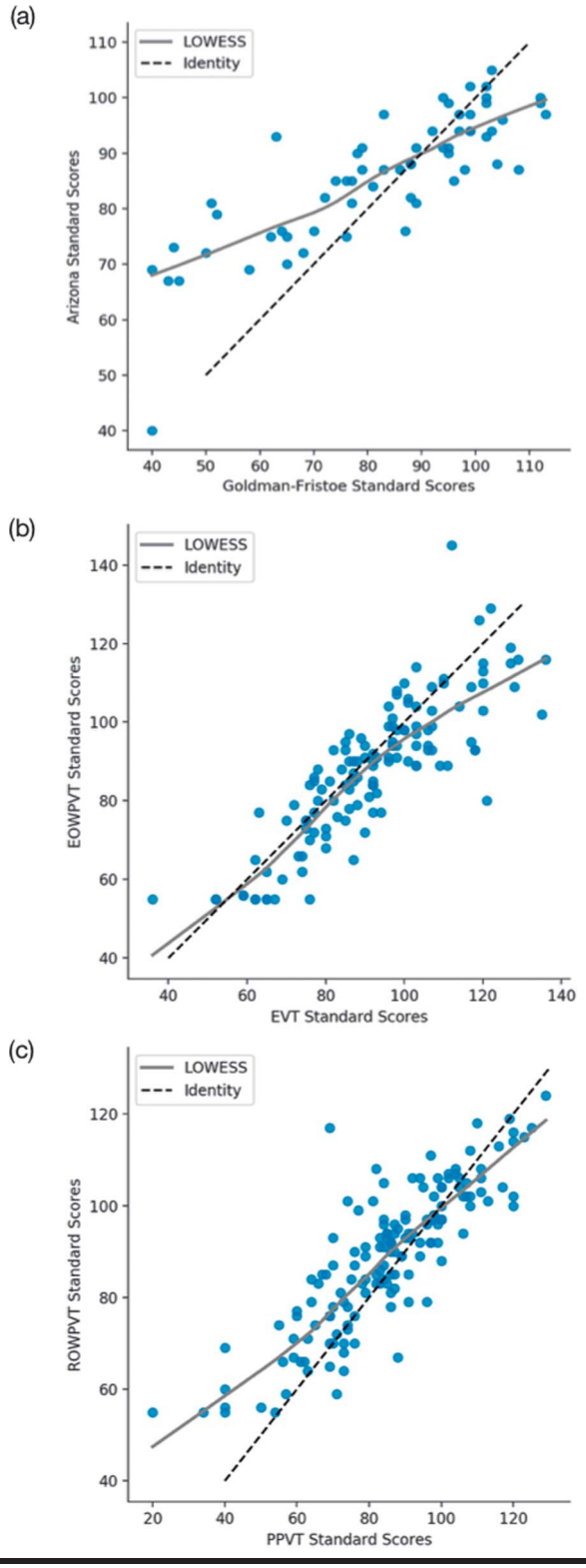


Figure 4. Distribution of standardized test scores for 3- to 5-year-olds, grouped by learning domains.

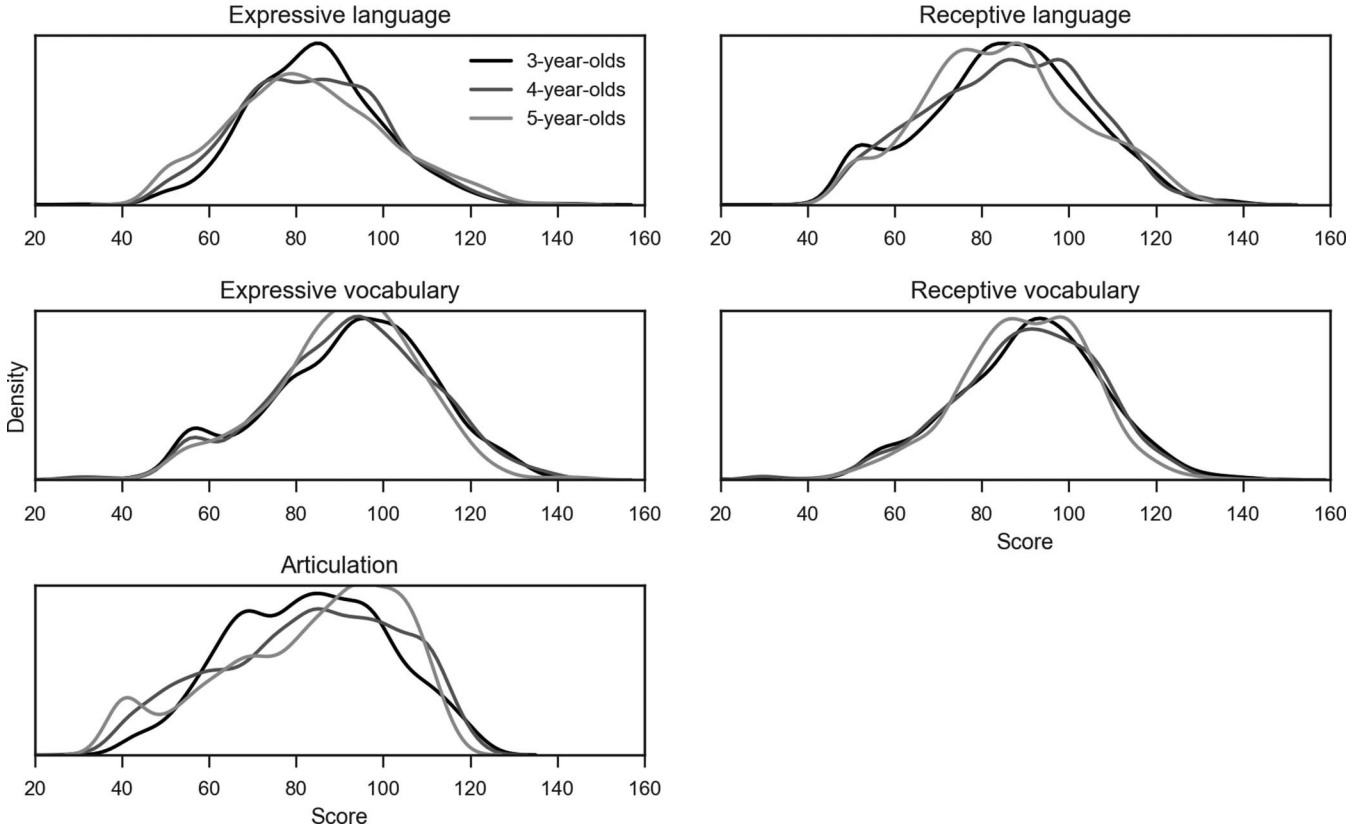
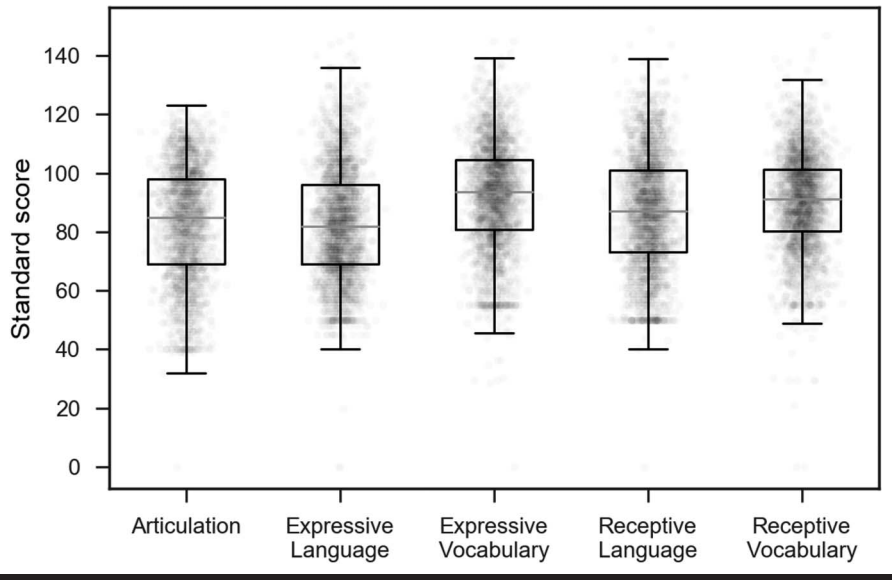


Figure 5. Distributions of standardized test scores across learning domains, pooled across ages. Height of line for each age represents the relative frequency of test scores.



listening skills, the impact of the age of enrollment in specialized programs on the development of spoken communication and listening skills, and the factors that influence outcomes of children with hearing loss enrolled in these highly specialized educational and therapeutic programs. The evidence suggests that many children with hearing loss can achieve age-appropriate spoken communication and listening skills when afforded the opportunity to receive appropriate instruction and therapeutic intervention by highly qualified professionals during early childhood. With the creation of the LSL-DR, future analyses will allow examination of factors that contribute to overall communication success, identification of opportunities to enhance intervention practices, and dissemination of findings to inform specialists, policy makers, and the families served by these programs.

Conclusion

The LSL-DR is the first reported international, longitudinal database collecting demographic and outcome measures on children with hearing loss who are receiving specialized listening and spoken language services. Aggregating data from more than 40 programs across the United States and beyond our borders provides an opportunity to examine key factors and trends that are often difficult to identify in a diverse, low-incidence population. Measuring outcomes and the variables that influence them is a critical next step in the field of listening and spoken communication development. Outcome measures not only provide information about the progress made by individual children, but also offer an opportunity to evaluate the effectiveness of teaching strategies and therapeutic approaches across similar populations. Measuring such outcomes as vocabulary growth, expressive and receptive language development, and functional communication skills among children with hearing loss is the foundation for determining effectiveness of educational intervention approaches and establishing best practice guidelines.

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