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Early Hearing Detection and Intervention Conferences: Cultural and
Pathological Messages

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Early Hearing Detection and Intervention Conferences: Cultural and Pathological Messages

Babies who are born with hearing loss have historically missed out on early language acquisition opportunities due to delayed diagnosis. Over 95% of deaf children are born to hearing families who would have no reason to suspect a hearing loss until typical language development is not evidenced (Marschark, 2010). Unfortunately, a dearth of language acquisition in early childhood has damaging effects on any subsequent language learning as well as social and emotional development. By waiting until children are of an age to evidence this lack of language, their overall language capability is already impeded, and the consequences of this delay will manifest throughout the child's lifetime (Mayberry, 2009; Moeller, 2000; Watkins, 1987; Yoshinaga-Itano, 2003).

Prior to legislation requiring Universal Newborn Hearing Screening (UNHS), the national average for age of diagnosis of hearing loss in the US was 30 months (Marschark, 2007). By this time a typically developing child with full language exposure would have a repertoire of between 500-1000 words, would be using these words in combination, and would have established a solid grammatical foundation for their language (Mayberry & Squires, 2006; Turnbull & Justice, 2011). The advent of legislation requiring Universal Newborn Hearing Screening (UNHS) has given families and professionals the opportunity to accommodate for a hearing loss during this critical time in language development. All 50 states have now established newborn hearing screening programs, and the aim of these programs is

to provide early intervention services before the child's first birthday (Sass-Lehrer, 2011).

Early Hearing Detection and Intervention (EHDI) is an organization that involves parents and professionals from a variety of backgrounds in order to share and disseminate important information relevant to early intervention services. This organization provides continuing education and a forum for discussion of matters pertaining to young deaf children and their families. The goal of the national EHDI annual meeting is to enhance service delivery to young deaf children and their families (EHDI Annual Meeting, 2014).

The topics discussed at these meetings are intended to enrich parent and professional understanding of what works best for young deaf children and their families, and to facilitate the delivery of these practices at the state level and local communities. The topics presented each year at the national annual EHDI conference are intended to share a variety of perspectives in order to meet the various needs presented by young deaf children and their families. Information focused on the auditory system and verbal communication, as well as information regarding American Sign Language and Deaf¹ culture are examples of variety in this discussion forum.

¹ "Deaf" written with a capital D indicates deafness as a culture, as opposed to a description of hearing status.

Theoretical Framework

Two distinct perspectives exist regarding deafness and appropriate linguistic, educational, and social approaches for deaf people. One perspective of the deaf views their hearing status in a primarily pathological way, compelling language acquisition and education to be tailored in a manner to ameliorate the hearing loss, thus, promoting the use of speech for communication (Lane, 1995; Hoffmeister, 1996).

In contrast to the pathological view of deafness, the social-cultural construct views Deaf people as members of a linguistic social minority. 'Hearing-impairment' is considered an inappropriate, derogatory term in this context. In the cultural paradigm, Deaf, Deaf community, and DEAF-WORLD are all used to describe an experience of life that emphasizes visual language and visual thinking, rather than one engrossed in impairments or dysfunctions of the auditory system (Hoffmeister, 1996; Lane, 1995).

In accordance with a cultural view of deafness, the Bilingual-Bicultural educational focus is on the deaf person's ability to interact and participate in both deaf and hearing cultures, rather than emphasizing individual deficits. The Bilingual-Bicultural conceptual model allows deaf people to be viewed as "competent human beings with unique skills and learning needs rather than as inept individuals who lack some physical attribute that needs correction" (Hoffmeister, p. 173).

The Deaf community does not view itself as having a communication disorder but rather represents a group that utilizes a visual language, American Sign Language, for the language of identity and exchange of ideas. The claim that one is in the Deaf world, or that someone else is not, is not a claim about hearing at all; it is an expression of self-recognition or recognition of others that is defining for all ethnic groups. The Deaf world is more concerned with social behavior, such as attitudes, beliefs, values, and language than with hearing status (Lane, 1996).

The pathological view of deafness is characterized, in contrast, with a preoccupation with the structure of the ear, audiological evaluations, hearing technologies, speech reading, speech therapy, cochlear implants, and disability. Hoffmeister presents evidence as to the biased emphasis on the pathological view in his review of special education textbooks (1996). In his study, the categories defined as pathological contribute one-third of the information in every chapter, with some chapters containing up to 50% of the discussion related to pathological perspectives and information. In contrast to this, the social/cultural viewpoint of deafness contributed only one out of 13 chapters devoting 20% of its content to this perspective (Hoffmeister, 1996). This is interesting because, as Hoffmeister points out, those in the role of educator would have absolutely no functional use for this kind of information.

In the case of early intervention, there is a need for professionals to be acquainted with this information in order to support parents' understanding. However, much like special education's stigmatizing and disproportionately

prevalent pathological vernacular, early interventionists' professional development materials have historically emphasized the pathological view of deafness. The strategies professionals use are based on the constructs established in Early Intervention educational programs and as such determine the success (or lack thereof) for deaf children (Hoffmeister, 1996).

As stated in the JCIH (Joint Committee on Infant Hearing) position statement for 2013, equity is absolutely necessary in the dissemination of information for parents of a child with hearing loss. The goal of increased inclusion of deaf/hard of hearing individuals in the paradigm of early intervention is also called for in this position statement. The 'Deaf Role Model' presented in the SKI*HI (Sensory Kids Impaired Home Intervention) model allows for this mentorship and support to take place. A Deaf role model (sometimes called a Deaf mentor) is a member of the Deaf community who interacts with young deaf children and their families in order to support the learning of American Sign Language, provide exposure to Deaf culture, and to be a strong language model for the family.

According to JCIH (2013), families who receive cultural input and are exposed to a bilingual, culturally competent environment have positive outcomes. Deaf children who associate with Deaf adults early have an opportunity to develop beginning knowledge through the use of ASL and develop English skills at a faster rate than children who do not receive Deaf mentor services.

Inclusion of the Deaf community, cultural competence and unbiased support of families with a child who has a hearing loss are all important goals for early

intervention that reflect the cultural view of Deafness. In practice, early intervention at the present time has not universally accepted these values, but there is a growing awareness of the importance of the cultural reality of deafness. Early intervention is, at its heart, an effort to maximize the potential of each child with a hearing loss. In this way, the perspectives on deafness stated by Hoffmeister (1996) that emphasize individual competence, cultural pride and self-esteem intrinsic to a cultural view parallel the goals of early intervention. This being the case, the inclusion of cultural messages is necessary in early interventionists' curriculum, and EHDI continuing education.

Early Hearing Detection and Intervention History

The history of Early Intervention (EI) services can be traced back to the Babbidge Report (United States, 1965) which urged the development and nationwide implementation of universally applied procedures for early identification and evaluation of hearing loss. These recommendations resulted in the development of the "High Risk Register," which was a questionnaire given to new parents that identified risk factors for hearing loss. If risk factors were identified, audiological testing was administered accordingly. One limitation of the High Risk Register was that infants without any risk factors were not given audiological testing, and were thereby unidentified under this method (Johnson & Seaton, 2011).

The Joint Committee on Infant Hearing (JCIH) was established in late 1969, and was composed of representatives from audiology, otolaryngology, pediatrics, and nursing. In 1970, JCIH advocated for early detection of hearing loss. JCIH had a

pivotal role in Early Hearing Detection and Intervention (EHDI) services in the US and internationally. EHDI was established as an organizational body in 2000. Since that time EHDI has held annual national and state level conferences for continuing education that address the needs and concerns of children with hearing loss and their families.

Early Hearing Detection and Intervention Current Practices

Newborns with hearing loss are now identified earlier than ever before, but identification in and of itself is not enough. In order to effectively capitalize on the child's critical period for language development, he/she must be identified and provided appropriate early intervention services. This timely and effective service provision is not available in all communities. To address this concern, the Joint Committee on Infant Hearing (JCIH) issued a statement of endorsement in 2013 that calls for all children who are deaf/hard of hearing and their families to have access to *timely* and *coordinated* entry into EI programs. This statement of endorsement defines "timely" as referral to part C services within two days of the audiologic evaluation, and implementation of services within 45 days (JCIH, 2013).

According to JCIH, an estimated one in four children who are deaf/hard of hearing are successfully tracked to an EI system. At the current time, only a few states are tracked into coordinated EI systems (JCIH, 2013). The Colorado Home Intervention Program (CHIP) and the Sensory Kids Impaired Home Intervention (SKI*HI) program (developed in Utah, but used in other states as well) are examples

of early intervention programs that monitor progress over time (Watkins, 1987; Yoshinaga-Itano, 2003).

The focus of the SKI*HI program is on parental training. The aim of this program is to teach parents how best to provide appropriate language stimulation for children with a vision or hearing loss. This program uses weekly home visitations by early interventionists in order to teach and model appropriate communication strategies to parents (Watkins, 1987).

According to Sass-Lehrer's "Guidelines for Effective Services," possible barriers to widespread adoption of effective early intervention services may be attributed to a lack of specialists who are able to evaluate an infant's hearing and a lack of professionals who are specially trained to work with infants who are deaf and hard of hearing and their families. Due to these deficits, professionals with limited knowledge often assume the responsibilities of providing services (Sass-Lehrer, 2011). These issues are addressed in the 2013 JCIH supplement to the 2007 Position Statement on Newborn Infant Hearing Screening (NIHS), Goal 3: "All children who are deaf/hard of hearing from birth to 3 years of age and their families have EI providers who have professional qualifications and core knowledge and skills to optimize the child's development and child/family well-being" (JCIH Position Statement, p. 7).

Qualified professionals with specialized preparation are essential for providing appropriate services and achieving successful outcomes for young children with hearing loss and their families (Sass-Lehrer, 2011). Parents who have

received the information via UNHS (Universal Newborn Hearing Screening) that their child has a hearing loss often still have questions and concerns about language, communication, education and opportunities for their child. Families recognize the need for support from professionals and other families with deaf and hard of hearing children, as they are often more understanding of the situation than their own family members (Meadow-Orlans, Mertens & Sass-Lehrer, 2003).

There are many communication options available for parents of a deaf or hard of hearing child, but these choices are typically categorized as either spoken or sign language options. According to a paper presented at the 2006 Alexander Graham Bell Association, in 1995, 40% of parents surveyed chose spoken language, and 60% chose signed language options. This statistic has radically changed, as reported in 2005, that 85% of families chose spoken language options compared to 15% who chose signed language (Brown, 2006).

This dichotomous language landscape for deaf children forces parents to choose either speech or sign language, with little or no background knowledge concerning either approach. Families often experience tremendous anguish as they try to make the best decision for their child, and professionals may add to their burden because of lack of information or strong biases (Sass- Lehrer, 2011). In the case of parents who go through the process of early hearing screening, many later report that they were given biased or incomplete information by the people conducting the screening (Marschark, 2010). To address this issue of bias, the JCIH 2013 Position Statement Supplement asserts several goals and recommendations:

Goal 1, Recommendation #2: Develop a mechanism that ensures family access to all available resources and information that is accurate, well-balanced, comprehensive, and conveyed in an unbiased manner.

Recommendation #2 c: Develop a mechanism that ensures that the information contained in the family resource manual provides parents/families with unbiased and accurate information through review by the state/territory EHDI committee or other designated body.

Goal 2, Recommendation #2: Identify the core knowledge and skills for service coordinators on the basis of evidence-based practices and the recommendations of professional organizations and national policy initiatives... Establish and implement professional development programs that include training in dissemination of information without bias.

Goal 3a: Intervention services to teach ASL will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.

Goal 10: Individuals who are deaf/hard of hearing will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels; their participation will be an expected and integral component to the EHDI systems.

Goal 11: All children who are deaf/hard of hearing and their families will have access to support, mentorship and guidance from individuals who are Deaf/Hard of Hearing (JCIH Position Statement, p. 20-21).

Professional bias toward one or the other approach is evident in the way EHDI programs are conducted, as exclusively favoring either a visual or auditory language approach (Brown, 2006). However, this methodological loyalty on the part of early intervention programs is not supported by what is known about language acquisition, in either hearing or deaf populations. There is no evidence to suggest that the use of signs or gestures by deaf children prevents or even inhibits their development of skills in spoken language, or in any other area (Mayberry, 2009; Lane, Hoffmeister, Bahan, 1996; Petito, 2000). Quite the opposite, gestures are an essential prelude to both spoken and signed language development, for both deaf and hearing children. Denying the use of gestures to deaf children, as is done in many spoken language programs, is more likely to negatively affect language, rather than help a developing deaf child (Marschark, 2007; Yoshinaga-Itano, 2003; Mayberry 2009).

Exposure to spoken language exclusively is not often successful for the prelingually deaf child either receptively-- speech-reading conveys roughly 15-30% of linguistic information--or expressively, in that only 25% of children with profound hearing loss were found to have intelligible speech at six years old, despite receiving early intervention services from birth to three years of age (Marschark, 2007). In contrast, a deaf child born in an environment that provided full visual language access from birth would have receptive and expressive abilities on par with hearing peers (Mayberry, 2009).

In evaluations of children's social adjustment, education, and language development, deaf children exposed to sign language as preschoolers show better progress than children raised in strictly speaking and listening programs (Marschark, 2007). While it is understandable that hearing parents, as well as professionals who work in the disciplines of speech and hearing would prefer auditory and spoken communication, there is no evidence to support the exclusive use of these methods for the majority of the deaf population (Marschark, 2007).

Developing a complete language foundation during the first few years of life is essential to any subsequent second language learning, which includes orthographic literacy. Deaf children given limited access to language during the critical developmental years demonstrate challenges in second language learning and reading ability that is not evidenced by deaf children who are given full visual language access from birth (Mayberry, 2009). The linguistic, cognitive, and social-emotional consequences of a limited ability to command language are apparent in the deaf adult population. Making the connection between 'hearing-impaired' children and the 'Deaf' adults they will become is essential when considering the best linguistic approach in an EI program.

Deaf children who are exposed to visual language consistently out perform those who are not, in virtually all developmental areas (Marschark, 2007). Yet, according to the Gallaudet Research Institute (2003), only about 27% of deaf children have families that sign regularly at home. Many children and parents are being short changed in their ability to communicate during the child's critical period

for language development. This lack of communication can have deleterious effects on every domain of the child's life (Marschark, 2007).

Purpose

The purpose of this study was to evaluate the messages being sent by Early Hearing Detection and Intervention in annual national conferences in regard to cultural and pathological views of deafness, as defined by Hoffmeister's coding categories Table IIa. and Table IIb. (1996). The categories established by Hoffmeister were used originally to demonstrate what kinds of cultural messages were being conveyed in Special Education text books in regard to deaf and hard of hearing people. In a similar fashion, this study evaluated the topics presented in EHDI national annual conference programs and categorized selected topics as being culturally or pathologically motivated.

Procedures

In this analysis, program information was collected from the annual national EHDI meetings, years 2002-2013, via the EHDI national meeting website (EHDI Annual Meeting, 2014). Using Hoffmeister's (1996) coding categories, key words presented in the titles of all topical sessions were be labeled as cultural or pathological, and displayed on an Excel spreadsheet. The categories used in this report were taken from Hoffmeister's 1996 study (Appendix A). Additionally, new categories emerged from the data itself. Descriptive statistics were used to analyze and discuss the results of this categorization, in order to determine the prevalence of cultural and pathological topics in EHDI conferences.

In this study the titles of topical and panel sessions were analyzed for the years 2002-2013. Plenary sessions were not included in the data analyzed. Each title analyzed was given only one value in the data reported. This means that even though a title may have contained more than one category, it was only counted once in the data used in this report.

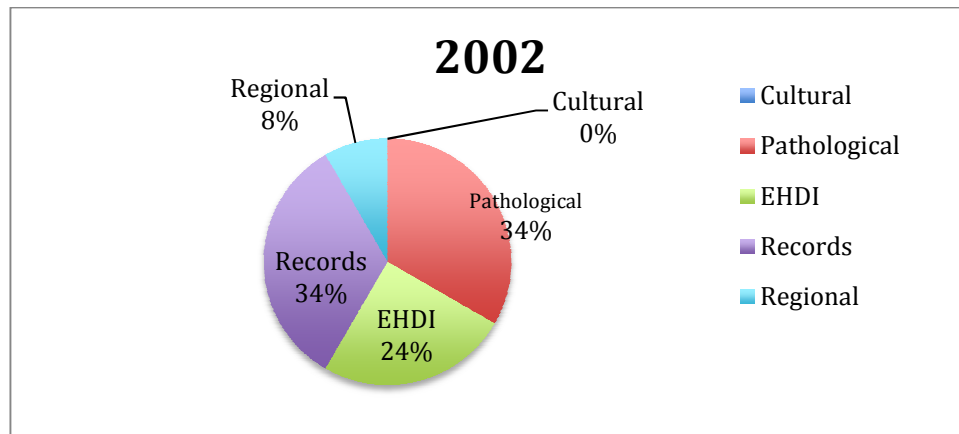
Many of the titles included in the EHDI topical sessions program included ambiguous information that did not easily or discreetly lend themselves to one category. For such titles, additional information about the subject matter was obtained by reading the abstract/Power Point for the presentation. These abstracts/Power Point presentations are available on the EHDI meetings website.

In keeping with the purpose of this study, the data was analyzed in order that the meaning conveyed in the topic determined its categorical placement, rather than words the title contained evaluated in isolation. With this purpose in mind, the word “Deaf” (capitalized) was not used as a cultural indicator, nor was “deaf” (not capitalized) used to indicate a pathological view of deafness. The terms “hearing impaired” and “hearing loss” were not considered pathological perspective indicators. Each title was considered as a whole, and in that consideration the key words that best described the overall meaning of the presentation were used to assign a category.

Findings: EHDI Conferences Years 2002-2013

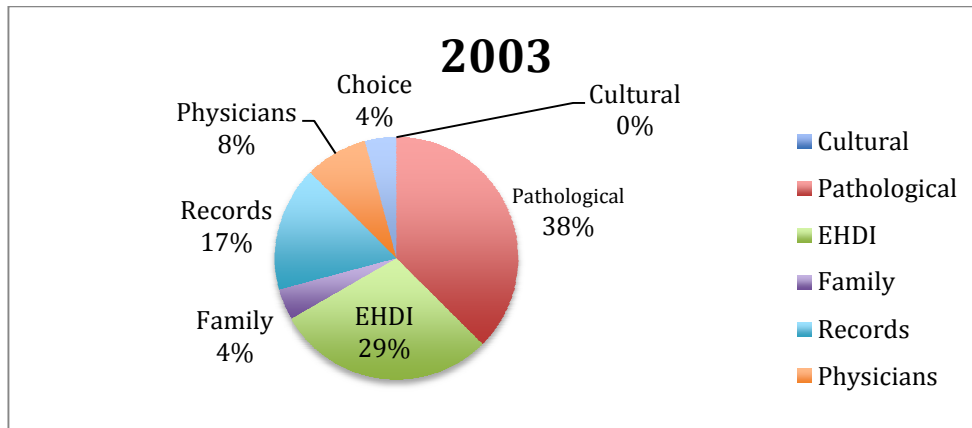
2002

In 2002 a total of twelve different lectures were presented. No “Cultural” topics were presented (0.0%). The largest categories for this year were “Pathological” and “Records” with four presentations (34%) in each. “EHDI” category had a total of three presentations (24%), and “Regional” category contained one presentation (8%).



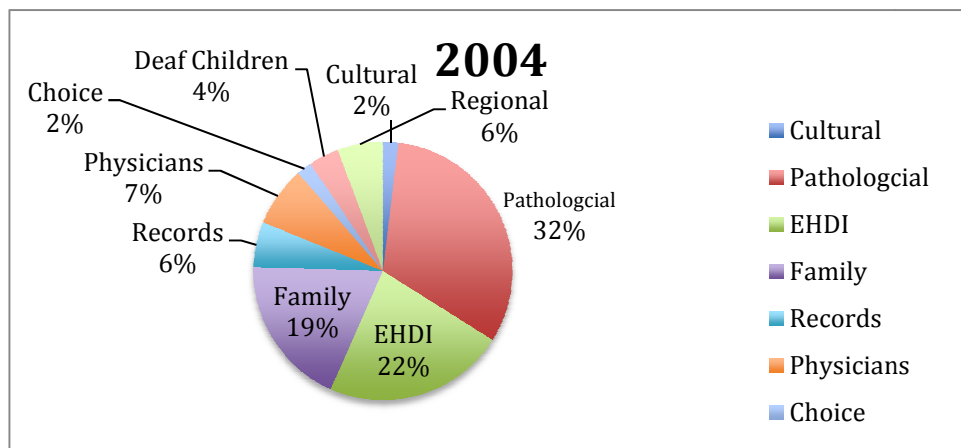
2003

In 2003 a total of twenty-five different lectures were presented. No “Cultural” topics were presented. The largest category in this year was “Pathological,” with nine presentations (38%). “EHDI” category had a total of eight different presentations (29%). “Records” category had a total of four presentations (17%). Physician category contained two presentations (8%). “Family” category had one presentation (4%), and “Choice” category contained one presentation (4%).



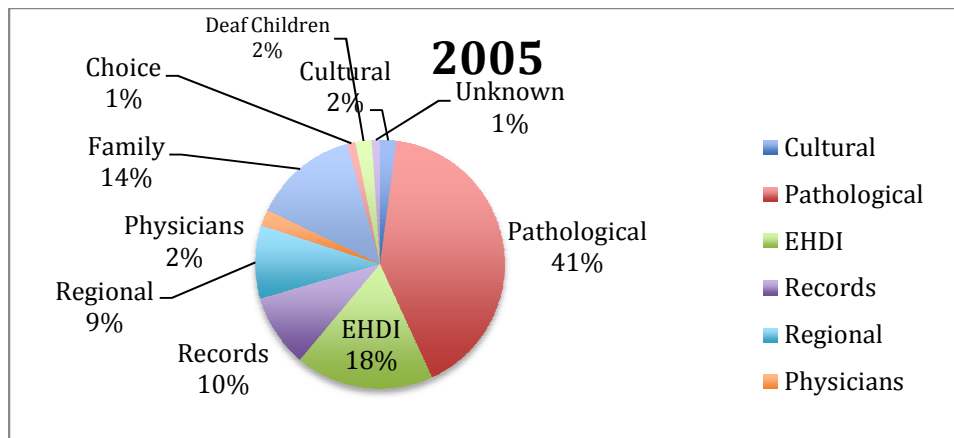
2004

The year 2004 had a total of fifty-three presentations. This year, “Cultural” category had one presentation (2%). “Pathological” category contained seventeen presentations (32%). “EHDI” category had twelve presentations (22%). “Family” category contained ten presentations (19%). “Physicians” category contained four presentations (7%). “Records” category contained three presentations (6%). “Deaf Children” category had three presentations (4%). “Regional” category contained two presentations (6%). “Choice” category had one presentation (2%).



2005

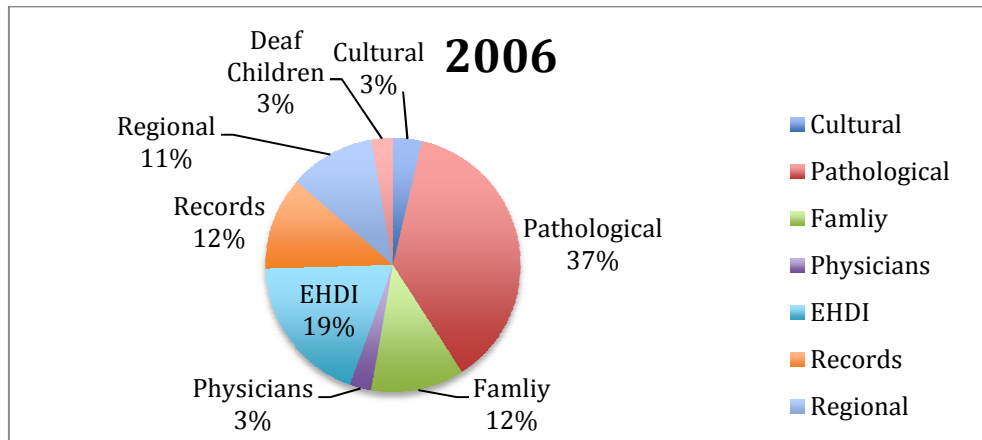
The year 2005 had a total of ninety-five presentations. “Cultural” category contained one presentation (1%). “Pathological” category contained forty presentations (41%). “EHDI” category contained seventeen presentations (18%). “Family” category contained thirteen presentations (14%). “Records” and “Regional” categories both contained nine presentations (10%). “Physicians” and “Deaf Children” categories contained two presentations (2%). “Choices” and “Unknown” categories contained one presentation (1%).



2006

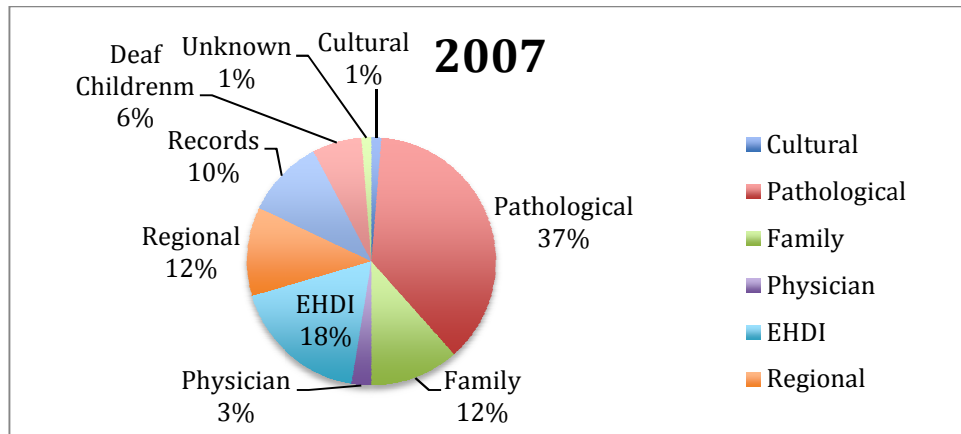
The year 2006 had a total of one-hundred and eleven presentations. “Cultural” category contained four presentations (3%). “Pathological” category contained forty-one presentations (37%). “EHDI” category had a total of twenty-one presentations (19%). “Family,” “Records” and “Regional” categories all had thirteen

presentations (12%). “Physicians” and “Deaf Children” categories each had three presentations (3%)



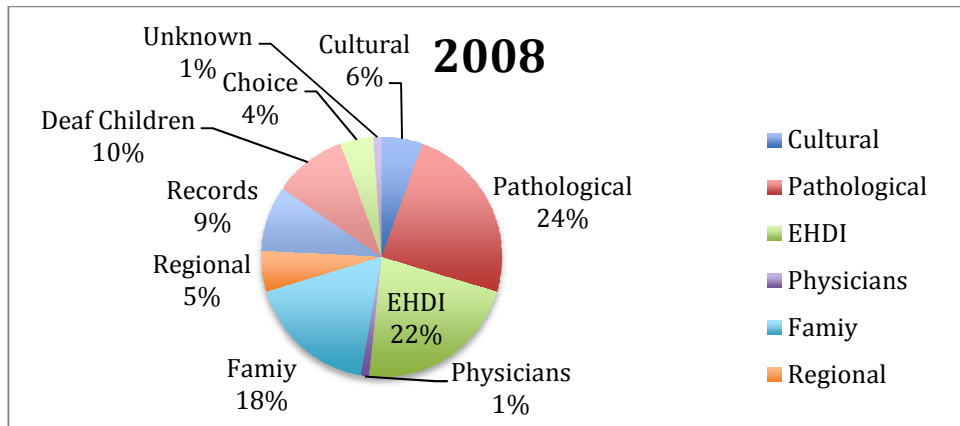
2007

The year 2007 had a total of seventy-eight presentations. “Cultural” category contained one presentation (1%). “Pathological” category contained twenty-nine presentations (37%). “EHDI” category contained fourteen presentations (18%). “Family” and “Regional” categories contained nine presentations each (12%). “Records” category contained eight presentations (10%). “Deaf Children” category contained five presentations (6%). “Physicians” category contained two presentations (3%) and “Unknown” category contained one presentation (1%).



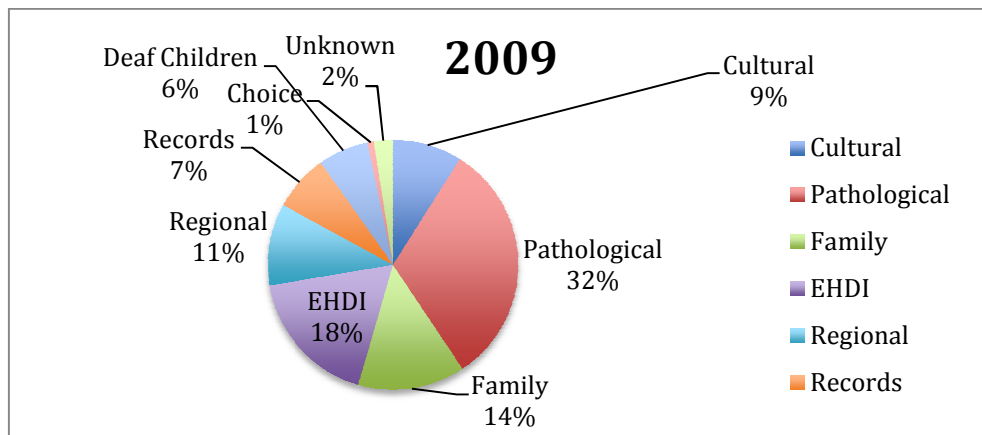
2008

The year 2008 had a total of ninety-one presentations. “Cultural” category contained five presentations (6%). “Pathological” category contained twenty-two presentations (24%). “EHDI” category contained twenty presentations (22%). “Family” category contained sixteen presentations (18%). “Deaf Children” category contained nine presentations (10%). “Records” category contained eight presentations (9%). “Regional” category contained five presentations (5%). “Choice” category contained four presentations (4%). “Unknown” and “Physician” categories contained one presentation (1%).



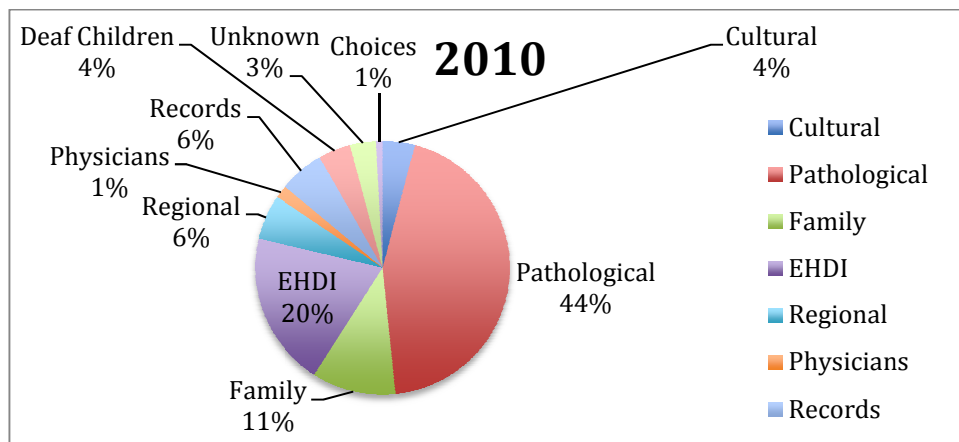
2009

The year 2009 had a total of one hundred and twenty-three presentations. “Cultural” category contained eleven presentations (9%). “Pathological” category contained thirty-nine presentations (32%). “EHDI” category had twenty-two presentations (18%). “Family” category contained seventeen presentations (14%). “Regional” category contained thirteen presentations (11%). “Records” category contained nine presentations (7%). “Deaf Children” category contained eight presentations (6%). “Unknown” category contained three presentations (2%). “Choices” category contained one presentation (1%).



2010

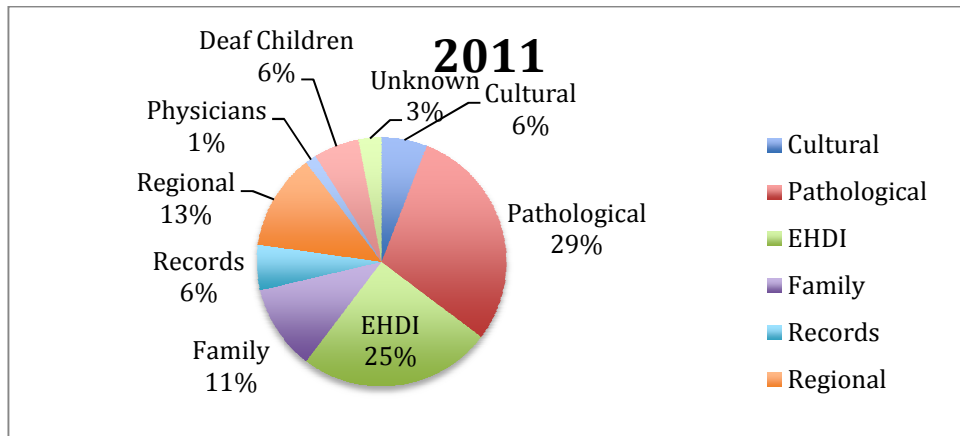
The year 2010 had a total of one hundred and twenty-two presentations. “Culture” category contained five presentations (4%). “Pathological” category had a total of fifty-four presentations (44%). “EHDI” category contained twenty-four presentations (20%). “Family” category had thirteen presentations (11%). “Records and “Regional” categories each had seven presentations (6%). “Deaf Children” category had five presentations (4%). “Unknown” category had four presentations (3%). “Physicians” category had two presentations (1%). “Choice” category had one presentation (1%).



2011

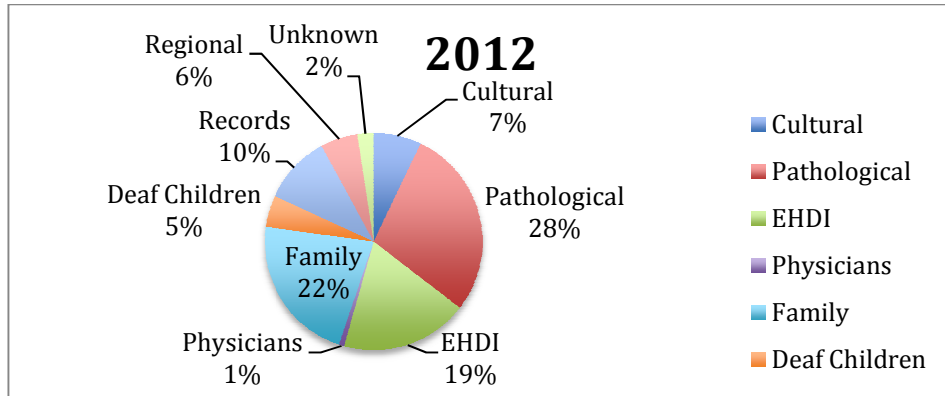
The year 2011 had a total of one hundred and thirty-six presentations. “Cultural” category contained eight presentations (6%). “Pathological” category contained forty presentations (29%). “EHDI” category contains thirty-four presentations (25%). “Regional” category contained seventeen presentations

(13%). “Family” category contained fifteen presentations (11%). “Records” and “Deaf Children” categories contained eight presentations (6%). “Unknown” category contained four presentations (3%). “Physicians” category contained two presentations (1%).



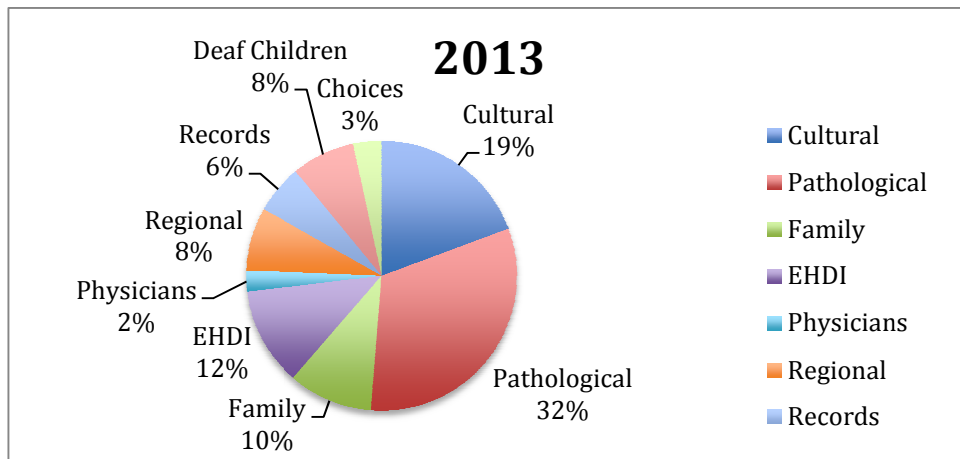
2012

The year 2012 had a total of one hundred and twenty-seven presentations. “Cultural” category had a total of nine presentations (7%). “Pathological” category had a total of thirty-six presentations (28%). “Family” category had a total of twenty-eight presentations (22%). “EHDI” category had twenty-four presentations (19%). “Records” category had thirteen presentations (10%). “Regional” category had seven presentations (6%). “Deaf Children” category had six presentations (5%). “Unknown” category contained three presentations (2%). “Physicians” category had one presentation (1%).



2013

The year 2013 had a total of one hundred and nineteen presentations. “Cultural” category had a total of twenty-three presentations (19%). “Pathological” category contained thirty-eight presentations (32%). “EHDI” category contained fourteen presentations (12%). “Family” category had twelve presentations (10%). “Regional” and “Deaf Children” categories had a total of nine presentations (8%). “Records” category contained seven presentations (6%). “Choice” category contained a total of four presentations (3%). “Physicians” category had three presentations (2%).



Discussion

New Categories

In the beginning of this analysis, two pre-established categories (Cultural and Pathological) were used to categorize the data, and those topics that fell outside of these categories were labeled “Other”. The “Other” category grew to overwhelming proportions, and across years analyzed, patterns began to emerge. The result of these patterns was the creation of several new categories. These new categories that emerged from the data were: EHDI, Family, Records, Regional, Physicians, Deaf Children, Choices, Exhibitor, and Unknown. Not every year contained every category.

The content of topical presentations at EHDI meetings can tell us a lot about the field of EHDI. The information presented at EHDI conferences not only informs practitioners for future work, but also reflects the trends and practices that are already taking place in the field. The information in this report is an overview of what EHDI currently presents as the most pertinent information to be disseminated to professionals and families. By evaluating this information, it is possible to see what topics/genres have been most valued from year to year, as well as what new information will be used by professionals and families in the future.

Using detailed categories, it is possible to evaluate this data in multiple ways that are beyond the scope of this report. There is a vast array of diversity within the topics presented each year, and within the categories designated in this report,

other categories could certainly be extracted. Issues related to technology, diverse populations and legal issues are just a few examples of topics that can be found within the new categories this report has created.

Within the created categories, (not labeled “Cultural” or “Pathological”), deeper investigation could reveal messages of either a pathological or cultural nature. However, in the interest of equity and clarity in the data, those topics that do not overtly display cultural or pathological messages have been assigned other categories. This study is a comprehensive exercise in “Judging a book by its cover” and with this in mind, the designation of categories was undertaken with the utmost care to ensure that the data was represented consistently and without bias.

EHDI. The “EHDI” category contains topics related to EHDI professionals and programs. The EHDI category is present in all years (2002-2013). Within this category are all titles that relate to: service delivery and improvement, legal issues, professional training and continuing education, access to and creation of resources, collaboration with other professionals, and online tools and resources for EHDI professionals to use. This category is primarily focused on Early Intervention as a job, and the contents of this category over the years show what topics are of continuing interest to EHDI providers. For example, topics related to using technology for service provision, resources and/or professional development was a topic that occurred in this category 6 out of the 12 years analyzed (2005, 2008-2012). Telepractice/ Teleintervention was discussed multiple times in later years,

(2010, 2011, 2012), indicating that this is a trend we can expect to see in early intervention in times to come.

Family. The “Family” category contains topics directly related to parents and families, as well as topical sessions focused on the needs and perspectives families have themselves expressed. The family category is present in the years, 2003- 2013. Parental satisfaction/perspectives/first-hand accounts are present in years, 2004-2006, 2008-2013. This demonstrates a consistent parental voice at EHDI conferences. In addition, this category contains topics related to non-English speaking families, and families living in poverty. This category addresses the specific needs a family might have, as well as strategies/materials for families, and perspectives expressed by the families themselves. In addition it is important to note that EHDI conferences are intended for family as well as professional attendance. Depending on the year, topical sessions are designated as “intended for families” specifically. Deaf children and their families are the most important “stakeholders” in early intervention. Parental participation in attendance and presenting at EHDI conferences demonstrates the value of parents and families in EHDI.

Records. The “Records” category is present in all the years analyzed, 2002-2013. This category contains topics that relate to data collection, data management within EHDI, integration of data, national reports pertaining to EHDI, and “loss to follow-up.” Topics related to integrated data systems appeared in 2003, 2004, and 2006-2013. This appears to be an important, ongoing issue related to record

keeping in EHDI. “Loss to follow-up” is another topic that pervaded this category. This term is used to describe the children who are identified at the initial hearing screening but do not come back for the follow-up hearing test. Topics related to loss to follow-up appeared in the years 2004-2013. In some years topics related to loss to follow-up appeared as many as four times (2013, 2011). Tracking information and maintaining contact with families identified through UNHS (Universal Newborn Hearing Screening) appear to be areas in which EHDI continues to engage in discussion and seek improvement.

Regional. The “Regional” category pertains to any topic that discusses EHDI as it relates to one particular region. The regional category appears in the years 2002, 2004-2013. This category is a perfect example of how EHDI conferences reflect the true nature of service delivery in various regions of the US and internationally. This category represents information that could be applied to any of the other categories, but has the specific characteristic of relating to one region. These topics have been singled out in order to examine which regions of the US contribute most to EHDI conferences, and what areas around the world are being discussed at EHDI conferences. Titles containing: International EHDI, Europe, British Columbia, South Africa, Costa Rica, England, India, and Pacific Rim Presentations have been presented from 2002-2013. Since the establishment of EHDI meetings in 2002, a total of twenty-nine different US states have presented topics. Several states have presented multiple times: Wisconsin, Massachusetts, and Indiana have presented the most, with four titles each.

Physician. The “Physician” category is comparatively small, but at least one title for each year (with the exception of 2002 and 2009) directly applies to physicians. This category was established because, in the case of EHDI, primary care physicians play an important role by supporting parents and helping them in the referral process. This group of professionals will obviously entertain discourse with parents regarding medical/pathological perspectives, since they are in fact medical professionals. It is unknown whether a physician will ever happen to encounter cultural information about Deaf people. In light of this, continuing education could be a viable opportunity for Deaf culture information to be prepared for/transmitted to physicians.

By creating a separate category for physicians, all titles relating to them could be carefully analyzed to determine if any cultural information regarding deafness was related to physicians in EHDI topical sessions. In 2004 one title “Transcultural Training for Perinatal Health Care Providers” addresses the issue of culture as it applies to health care providers who work with new mothers and families. However, this reference to culture is in terms of the world’s ethnic and religious cultures, not in terms of Deaf culture specifically. There were no other culturally related titles that apply to physicians in EHDI annual conferences years 2002-2013.

Deaf Children. The “Deaf Children” category is present in the years 2004-2013. This category includes information about deaf children’s development, assessment, transitioning into school, strategies to use with babies and young

children, as well as special interest groups of children who are deaf. Such groups are: deaf and blind children, deaf children with disabilities, deaf children in poverty and deaf children who are medically fragile.

Choices. The “Choices” category was established to separate all topics that pertain to parental choice for communication options. While this subject is addressed in several other categories in less obvious ways, the titles that explicitly address the issue of choice were placed in this category. The years containing this category are: 2003, 2005, 2008-2010, and 2013. Cultural and pathological perspectives held by professionals can influence parental choice, making the subject of choice relevant to this report.

Topics in this category include: parental perspectives on decision-making, long-term consequences of language choices, and other titles that are concerned with the decision making process. Of interest for this report was how many times the subject of choice was portrayed in a dichotomous, ‘either or’ fashion. The topic of parental choice was presented as dichotomous in two titles in 2013 (“To Sign or to Speak? Exploring Diverse Pedagogies of Language in Education” and “Spoken English and American Sign Language: Let the Child Lead You”) In the year 2010 parental choice was presented as dichotomous in one title (“Auditory/Visual Communication... What Works”).

When considering these titles it is important to realize that they have been categorized out of context. The research procedures employed in this analysis do not allow for an in-depth understanding of these presentations, and whether or not

information supporting bilingual acquisition of auditory and visual language was addressed. However, in the titles and abstracts for these presentations ASL and spoken English are presented as having separate, discreet implications related to learning and culture.

Exhibitor. The “Exhibitor” category was only present in one annual conference (2008). The two presentations in this category were related to products being exhibited at the conference. This category will not be used in any further discussions in this report.

Unknown. The “Unknown” category was created in order to find a place for titles that are expressed with extremely vague implications or excessive literary flourish. Titles such as “Home, Home on the Range” and “Can You Tell Me About...” (2009), are examples of titles designated in this category. While additional investigation (such as the reading of an abstract or Power Point presentation) was a research procedure employed in the designation of many titles, the connotation and designation assigned to each topic has to match specific words the title contains. In some circumstances the title contained no viable keywords to include in a category. Such presentation titles were designated to the Unknown category. This category will not be used in any further discussion in this report.

Cultural and Pathological Categories

Pathological. The “Pathological” category contains all information that addresses deafness as pathology. Any other pathological/medical topics (e.g. medically fragile deaf children, or deaf children with Down Syndrome) have been

placed in the category Deaf Children. Only pathological discussion about hearing was placed in this category. Titles in this category relate to a variety of topics in the field of audiology, hearing and hearing loss, speech and auditory prostheses. In order to maintain a clear picture of precisely what each topic of discussion was, many new topical categories were added. Some titles matched well with Hoffmeister's (1996) categories, but many others were only somewhat related or not at all. In order that the report reflect clearly what is taking place at EHDI annual conferences many new topical categories were added each year to reflect important details in the titles.

The pre-established topical category "Audiological Measurement" includes titles that contain information about various tests of hearing. These are: OAE (Otoacoustic Emissions), ABR (Auditory Brainstem Response), ASSR (Auditory Steady State Response), AEP (Auditory Evoked Potentials, hearing diagnostic, hearing evaluation, hearing test. This category is separate from the "Hearing Screening" category that emerged from the data. This was done in order to see how often audiological measures were discussed separate from hearing screening. Hearing screening is the first step in EHDI, and as such it would be reasonable to expect many topical sessions to be devoted to this subject. By considering these topics separately, the category for audiological measurement is not heavily weighted without details that explain why.

The “Etiology” topical category taken from Hoffmeister (1996) includes the topics: cytomegalovirus, auditory neuropathy, causes of hearing loss, congenital hearing loss, etiology and meningitis.

Genetics and bloodspot testing are other topics that were present in many years and these tests were included as separate topical categories. Bloodspot testing was presented in a topical presentation in 2009, 2012, 2013. Genetics testing for deafness was presented in 2002, and 2005-2007, 2012.

Cultural. The “Cultural” category contains topics related to bilingualism, audism, Deaf adults as mentors, literacy, ASL, visual environment, and perspectives of Deaf adults. This category’s primary focus is Deaf Culture. Topics related to ethnic culture have been placed in the “Deaf Children” and “Families” categories. The cultural category is comparatively small in relation to the pathological category. The years 2002 and 2003 contained no titles that related to Deaf Culture. 2004, 2005, 2007 contained one title in this category. Cultural topics increase in subsequent years (2006 contained four titles, 2008 contained five titles, 2009 contained eleven titles, 2010 contained five titles, 2011 contained eight titles, 2012 contained seven titles, 2013 contained twenty-three titles).

In this category what most often appeared was bilingualism and Deaf mentorship. From the year 2002-2013 topics related to bilingualism were presented fifteen times, and Deaf mentorship topics were presented six times.

Use of technology appeared in this category, as it did in many others. The focus for these titles related to ASL access for the family. In 2009 one topic relates to

the use of videophones for Early Sign Language Instruction. EHDI conferences are clearly an ideal venue for sharing creative ideas in order to overcome challenges in the field of early intervention. Many topical presentations discuss the use of technology to provide access to services, across all categories. ASL learning opportunities and cultural contact in this medium are presented in the years 2009, 2011, and 2013.

Limitations

This report is unable to encapsulate and convey everything that happens at EHDI conferences. Poster sessions, intra-professional dialogue, as well as the presenters' attitudes are all factors that influence cultural and pathological messages. Additionally, this analysis can not report the impact of topical sessions on the individual professionals that attend.

Within categories not labeled "Cultural" or "Pathological," messages about either subject are inevitably being conveyed. Topics labeled "Pathological" in this report may in fact contain cultural content. Likewise, topics labeled as "Cultural" may in fact support a pathological view of deafness. Depending on the content of the presentation and the attitude of the presenter, any of the findings in this report could easily change.

All the topics were categorized based on the designations of one researcher. Reliability is not strong in this report. Having an inter-rater would improve the reliability in this analysis.

Additionally, this study is only focused on the EHDI meetings that happened at a national level. There is no way to know how much of this information is transmitted to EHDI providers in their communities, or depending on the community, whether early intervention providers participate in EHDI conferences in any way. In this way, the validity of this report is not strong.

There are many organizational bodies that host annual meetings related to early intervention, and this report has no information regarding professional participation in EHDI conferences. Gathering information about local participation in EHDI by early intervention service providers would enhance the validity of this analysis.

This study is meant to be a snapshot of EHDI national annual conference content in order to get a sense of what topics are discussed most prevalently in EHDI continuing education conferences. This report has not conducted an in-depth analysis of all materials/information presented at every EHDI conference. Furthermore, this report has no way of measuring the attitudes of the presenters, which is a critical element in the issue of cultural and pathological messages being disseminated.

Implications

The analysis of EHDI conferences years 2002-2013 demonstrates clearly that cultural topics are presented in vast disproportion to pathological topics regarding deaf children. The pathological category dominated each annual meeting, containing more topical sessions than any other category for every year EHDI conferences have

been in session. There is no question that many of the topics presented in the pathological category are important in EHDI (i.e. Newborn Hearing Screening), and that it is essential for professionals working in the field of EHDI to have access to the most current information regarding these subjects. What this report demonstrates is the contrast between important pathological information and *equally important* cultural information.

The years 2002 and 2003 contained no topical sessions with culturally related content, and subsequent years of annual meetings presented very little cultural information regarding Deafness. The year 2013 emerged as a year for change in reference to cultural information regarding deafness, with 19% of the topics presented that year relating to culture. The year 2013 had the most topical sessions devoted to cultural information, and the beginning years of EHDI (2002, 2003) had the least discussion of cultural topics.

If early intervention professionals ever hope to improve outcomes for deaf children it is imperative that they provide families with tools and information supported by current, quality research. Providing professional access to such research is the responsibility of organizational bodies such as EHDI, ASHA (American Speech and Hearing Association), AAA (American Academy of Audiology), NCHAM (National Center for Hearing Assessment), the American Society for Deaf Children, and many others. It is of critical importance that accurate, balanced information is presented in these venues. Professional exposure to cultural information about deafness has been very limited in EHDI conferences held 2002-

2013. Since 95% of deaf children are born to hearing parents, early interventionists are necessarily the bridge between young deaf children and the Deaf community (Marschark, 2007). It is vital that early intervention professionals are provided access to cultural information regarding deafness in order to best provide language and identity access to young deaf children.

Directions for Future Research

As stated in the limitations, it is important to know what conferences professionals in early intervention attend each year. A study of early intervention professional participation at different state/national level EHDI/other early intervention conferences, would demonstrate where professionals actually get their information.

In order for more detailed information to be obtained, states/organizations would first need to establish a record keeping system/database where annual conference presentation materials can be found. At the current time EHDI is exceptional in providing such detailed information. Many other organizations, particularly at the state level, do not.

Gauging the communication between local and national organizations would contribute important information to the question of what information early intervention professionals have access to via continuing education. Whether information presented at the national level ever reaches local professionals determines whether or not deaf children are actually impacted by EHDI national conferences.

Appendix A

Coding Categories Table IIa. and Table IIb. (Hoffmeister, 1996)

TABLE IIa. Topics displayed in table of contents related to cultural issues and the deaf

Topics	Books												
	1	2	3	4	5	6	7	8	9	10	11	12	13
(A) The Deaf community	0	X	0	X	0	X	0	0	0	0	0	0	0
(B) American Sign Language	X	0	0	0	0	0	0	0	0	0	X	0	0
(C) Culture	0	0	0	0	0	0	0	0	0	0	0	0	0
(D) Bilingualism	0	0	0	0	0	0	0	0	0	X**	0	0	0
(E) Deaf in any heading*	0	0	0	0	0	X***	X	0	0	0	0	X†	0

*Other than topic A.

**'... , I'm just Deaf' part of anecdotal statement in chapter.

***'... , parents who are Deaf' part of an anecdotal statement included in chapter

†'Multicultural issues' refers to discussion of ethnic non-white Americans

TABLE IIb. Topics displayed in table of contents related to pathological view

Topics	Books												
	1	2	3	4	5	6	7	8	9	10	11	12	13
(A) Structure of the ear	X	X	X	X		X	X	X					
Hearing mechanism											X	X	
(B) Causes/etiology	X	X	X	X		X	X	X	X		X	X	
(C) Audiological measurement	X	X	X	X	X	X	X	X	X		X	X	X
(D) Communication approaches							X						
Manual communication	X	X	X					X					X
Oral communication	X	X	X					X					
Total communication	X	X						X				X	
(E) Technology							X						
Hearing aids		X							X	X			X
Cochlear implants		X		X									

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